

Parents' and carers' understandings of the nature and purposes
of parent-based intervention groups delivered by
the paediatric Speech and Language Therapy service in
Telford & Wrekin and Shropshire Primary Care Trusts:
an exploratory study

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Declaration

The work is original and has not been submitted previously in support of any qualification or programme.

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Abstract

Speech and language therapists regularly offer indirect group interventions providing parental advice or training, rather than direct treatments for communication-disabled children. Although this has been found to benefit children, there has been little research into the impact of such parent-based intervention groups on parents themselves. This is despite evidence that parents and speech and language therapists have differing perceptions regarding aspects of speech and language therapy and children's communication development.

The aim of this study was to explore parents and carers' experiences of attending parent-based intervention groups in a local context, in order to investigate their perceptions of the nature and purposes of the groups they had attended and to develop a preliminary theoretical understanding of their experience.

Nine mothers and one father who had completed at least one parent-based intervention course were interviewed. This generated descriptive qualitative data, which was analysed using grounded theory approaches to reflect the parents' priorities and concerns. Themes of parents' experiences of intervention sessions, parental gains during session attendance, intervention facilitating processes of personal change and empowerment, and impacts of parent-based intervention courses in the wider context, were identified.

The study findings were used to produce a description, grounded in the data, of parents' understandings of the nature and purposes of parent-based intervention groups in speech and language therapy. Connections were made between the role played by the groups in the experience of parents in the current study and processes of parental adaptation and empowerment described in the literature on chronic illness and disability in children. A theoretical model of parents' experience of parent-based intervention groups was also developed.

This study provides a preliminary overview of parents' experiences of parent-based intervention groups and includes a number of findings that support discrete observations and suggestions extant in the literature. It adds to the information available on parents' perceptions of speech and language therapy and indicates areas for further research into the costs and benefits of intervention from a parental perspective. The study findings, connections identified between the groups and processes of parental adaptation and empowerment, and the theoretical model presented have potential implications for clinical practice in the local area and may be transferable to other settings. However, the study was limited in size and scope and further research to test these findings will be required.

Chapter 1

Introduction

1.1 Background and rationale

When providing speech and language therapy to children, interventions may be offered which are not administered directly to the child, but indirectly through advice or training provided to the child's parent(s) or primary carer(s). These parent-based interventions have become standard treatment modes in the field (Glogowska & Campbell, 2000), and are used to address a range of communication difficulties (Royal College of Speech and Language Therapists, 2006). They may be provided for parents on a one-to-one basis, but are widely delivered in group settings (Girolametto & Weitzman, 2009); there is evidence that both modes of delivery are associated with clinical benefits for children (for examples, see Baxendale & Hesketh, 2003; McCathren, 2010).

Outside speech and language therapy, parent groups have been advocated as cost-effective for the provider (Cunningham & Davis, 1985), and beneficial for parents (Behr, 1997). However, within speech and language therapy the evidence for cost-effectiveness is inconclusive (Boyle, McCartney, O'Hare, & Forbes, 2009; Gibbard, Coglan, & MacDonald, 2004) and few of the presumed benefits for parents have been evaluated through research. Nor have the costs of such interventions to parents themselves been assessed (Gibbard et al., 2004). Instead, more studies have focused on clinical outcomes, and on discrete measures of satisfaction or stress. Hence, parents are currently offered speech and language therapy parent-based intervention groups based on

clinical outcomes for their child, but with limited evidence regarding cost-effectiveness for providers or any forms of costs and benefits to themselves.

The focus of this research was to investigate parents' experiences of these groups. There were several reasons for doing this. In the first place, parent-based intervention involves communicating concepts about childhood communication difficulties and therapy techniques to parents. However, there is some evidence to suggest that parents have different understandings from speech and language therapists regarding both the nature of children's communication difficulties (Marshall, Goldbart, & Phillips, 2007), and what speech and language therapy entails (Glogowska & Campbell, 2000; Lyons, O'Malley, O'Connor, & Monaghan, 2010). For example, Lyons et al. found that parents entering an intervention process expressed uncertainty over matters that the clinicians had considered self-explanatory; they argued from this that clinicians need to explore parents' views and develop shared meanings if they are to work together effectively. Exploring parents' current perceptions of parent-based intervention groups could inform attempts to develop such shared meanings.

Exploring parents' perceptions of parent-based intervention groups could also identify useful information regarding costs or potential harm to parents associated with the intervention. Bray (2002) stated that costs to parents are not necessarily apparent to clinicians, suggesting that influences and calls on parents' time exist that are unknown to professional service providers. There is evidence that parents balance benefits against costs when considering therapy interventions (Glogowska, Campbell, Peters, Roulstone, & Enderby, 2002) and

that if parents perceive costs as outweighing benefits engagement may be prevented or diminished (Glogowska & Campbell, 2000). Some study findings have indicated that the experience of administering interventions advised by a speech and language therapist may be stressful or even distressing in some instances for some parents. For example, Goodhue, Onslow, Quine, O'Brian, and Hearne (2010) found that while parents attending parent-based interventions generally expected to help their child practise exercises between one-to-one speech and language therapy appointments, they expressed surprise and anxiety at the level of responsibility they were asked to accept for developing their child's communication skills. Although these studies related to individually administered interventions, it is possible that similar negative impacts exist in parent-based intervention groups.

Another reason to undertake the study was that identifying parents' perceptions of parent-based intervention groups may contribute insights into how the intervention process works, which could then be applied to improving clinical effectiveness. Discussing parent education groups more generally, Campbell and Palm advocated "[t]he identification of promising practices through increased research and reflective practice..." (Campbell & Palm, 2004, p. 22). Understanding practice from the parents' perspective in order to improve procedures has also been advocated in the fields of education (Lindsay & Dockrell, 2004), and speech and language therapy (Lyons et al., 2010).

The local context for this study was the Speech and Language Therapy service based in Telford & Wrekin Primary Care Trust's Services for Children and Young People between April 2009 and July 2010. During that period,

speech and language therapists working within the Trust offered parent-based intervention groups to address a range of communication difficulties across two Trusts covering the county of Shropshire. The intervention groups offered by the service included three types discussed in this study; these were Early Communication Skills groups, courses from the EarlyBird programme, and Makaton training courses.

Early Communication Skills groups are offered to parents and carers of children aged between two years and three years three months, who have been identified with limited communication for their age. Since in young children it is not always possible to differentiate between primary communication difficulties and those which are secondary to other developmental issues (Law, Garrett, & Nye, 2004), the children whose parents attend these groups may subsequently be diagnosed with conditions such as developmental delay or autistic spectrum disorders. Each Early Communication Skills course uses features of published parent-based intervention programmes, such as “It Takes Two to Talk” (Conklin, Pepper, Weitzman, & McDade, 2007) alongside other elements; adaptations of this programme are permitted to address local needs (Girolametto, Greenberg, & Manolson, 1986). In Shropshire, courses are delivered over three to six group meetings depending on the clinic, with each session lasting between one and a half and two hours; the facilitators are all speech and language therapists.

EarlyBird and EarlyBird Plus programmes were developed by the National Autistic Society. EarlyBird, in use since 1997, was designed to address the needs of parents with a preschool child with autism (National Autistic

Society, 2007). EarlyBird Plus was developed in 2003 (Shields, 2004). While parents/carers attend the EarlyBird Programme, both parents/carers and teachers/teaching assistants attend EarlyBird Plus, and work together to address the needs of children in Early Years and Key Stage One provision. Both programmes are delivered over a three month period (Shields, 2004), with a follow-up session at three months for EarlyBird (Shields & Stevens, 2008) and six months for EarlyBird Plus (Shields, 2004). In Shropshire, both courses are delivered by multi-disciplinary partnerships of a learning support advisory teacher and a speech and language therapist; both professionals have accredited EarlyBird/EarlyBird Plus training and experience in autistic spectrum disorders.

Makaton courses offer training in the use of the Makaton language programme. This programme uses signs and symbols to support current communication and facilitate communication development (Leverton & Peden, 2008). Beginner's training courses run over four sessions, each lasting two hours and forty-five minutes (The Makaton Charity, 2011). Within Shropshire, Makaton courses are facilitated by a speech and language therapist and a specialist teacher.

All three interventions involve group sessions, where participants meet and carry out activities provided by the professional facilitators; there is usually a short "coffee" break during each session. In Makaton courses, the main activities are the teaching of Makaton signs and activities to practise these with other members of the group. For example, a group of signs may be taught, and the group members are then asked to hold short conversations using the signs

learned. In Early Communication Skills and EarlyBird groups, information is provided about communication development, the child's diagnosis, and adult-child interaction. Activities such as role-play are used to enable participants to experience the child's role in communication situations, and the information and insights gathered are applied to individual children through activities that encourage reflection by individual adults and discussions in the group. Both EarlyBird and Early Communication Skills courses also include two or three one-to-one sessions, where parents are videoed interacting with their child and individual issues are discussed. The videos are usually presented in the group sessions and discussed in pairs or small groups.

1.2 Research question

The research question chosen was:

How do parents and carers understand the nature and purposes of parent-based intervention groups delivered by the paediatric Speech and Language Therapy service in Telford and Wrekin Primary Care Trust?

It was anticipated that by exploring parents' perceptions of the nature and purposes of the groups they attended, a range of parental experiences and understandings of parent-based intervention groups would be identified. This would provide a description of parent-based intervention groups from a parental perspective, enable the development of a framework for understanding how parents experienced the groups, and possibly indicate areas for future study.

1.3 Aims and objectives of the study

The overall aim of the study was to conduct a preliminary exploration of parents and carers' experiences of attending parent-based intervention groups. In order to achieve this, a qualitative strategy was chosen to obtain descriptive data. Grounded theory approaches were selected to ensure that the findings and conclusions of the study reflected the priorities and concerns of parents, and the following objectives were identified:

- to explore parents' and carers' perceptions of the purposes of parent-based intervention groups;
- to explore parents' and carers' views of the nature (characteristics) of parent-based intervention groups;
- to explore issues identified during the study as emergent objectives as appropriate to grounded theory approaches;
- to develop a preliminary theoretical understanding of parents' experience of parent-based intervention groups.

1.4 Structure of the report

This report is divided into five chapters. Following this introduction in Chapter 1, a review of the literature is presented in Chapter 2. In Chapter 3, methodology of the study is described and discussed. Findings from the study are presented in Chapter 4. Finally, discussions and conclusions are presented in Chapter 5.

1.5 A note on terminology

Throughout this report, certain terms are used interchangeably or simplified in order to facilitate ease of reading and avoid use of abbreviations.

The terms “speech and language therapist” and “speech and language therapy” have been used as general terms to include variants such as “speech and language pathologist” and “speech and language pathology”.

The terms “clinician” and “therapist” have been used to denote “speech and language therapist”.

The term “professional” has been used to denote speech and language therapists and other professionals such as teachers.

Chapter 2

Literature Review

2.1 Introduction

In this chapter, literature relevant to this study is reviewed. A systematic literature search was carried out to locate relevant sources; details of the search strategy and search terms used are presented in Appendix A.

When using grounded theory approaches, the literature review has been considered somewhat problematic and review strategies have varied (Denscombe, 2007). While it has previously been argued that the literature review should be deferred to avoid influencing the researcher (Glaser & Strauss, 1967), grounded theorists generally take a more nuanced approach to this issue (Charmaz, 2006). In this project, literature was reviewed prior to the study to explore the knowledge base within speech and language therapy and elsewhere regarding parent-based intervention and group working, and to ascertain what research had been carried out into parents' experiences within speech and language therapy. Methods used to explore parents' views and use of grounded theory methods in speech and language therapy research were also reviewed at this stage. As the study progressed, additional literature reviews were undertaken relating to concepts arising during data analysis.

For some areas of the literature reviewed, sources specific to speech and language therapy were limited, and sources from other disciplines were therefore included. These have been indicated in the text.

2.2 Parent-based interventions in speech and language therapy

Within speech and language therapy, working with parents to modify the environment around communication-disordered children has been advocated since the 1950s (see Backus & Beasley, 1951). Parent-based interventions have been reported as addressing both primary and secondary communication difficulties, on an individual and a group basis. Examples have included individually administered parent-child interaction therapy for children who stammer (Kelman & Nicholas, 2008), parent-based intervention groups for children with delayed communication skills (Gibbard, 1998; Girolametto & Weitzman, 2009), and parent-based interventions for children with cerebral palsy (reviewed by Pennington, Goldbart, & Marshall, 2004).

Two models of facilitating communication development have been described in the literature, influencing both group and individual parent-based interventions. One approach (exemplified by Fey, Cleave, Long, & Hughes, 1993) is didactic/directive, and is aimed at changing the child's communicative behaviours. New skills, or new applications of current skills, are selected as targets and parents learn how to train the child, within more or less naturalistic activities, to produce these. The other model (described in Girolametto, 1999) is interactive and non-directive; parents alter their own responses to the child's existing behaviours in order to facilitate increased communication through following the child's lead. Elements of both models may be combined (for examples, see Fey et al., 2006; Kelman & Nicholas, 2008; McCathren, 2010).

In the United Kingdom, a programme following the directive model of language facilitation was published in 1998; the "Parent-based intervention

programme” (Gibbard, 1998) used a sequence of specified therapy goals, demonstrating possible strategies and requiring parents to work in groups to devise further activities for use with their language delayed child. However, for English speakers, the best-known parent-based intervention group protocols are the Hanen Programmes, which are based on the interactive model of communication facilitation (Girolametto et al., 1986; Girolametto & Weitzman, 2009). The most commonly used programme is Hanen’s “It Takes Two To Talk” (Conklin et al., 2007), with approximately 15,000 speech and language therapists worldwide trained in the protocol by 2009 (Girolametto & Weitzman, 2009).

The theoretical rationale for parent-based interventions presented in speech and language therapy literature is limited. What does exist has been based on Bronfenbrenner’s systems ecology model of human development (Bronfenbrenner, 1979), in which he described each person’s development as occurring not in isolation, but through interaction between the individual (the “developing person”) and their environment . While Bronfenbrenner’s aim was to alert researchers to the limitations of research on individuals without due regard to their wider environmental context, his model has become a frequently cited justification for parent-based and other indirect interventions across a range of disciplines. Hornby (2000), writing in the field of education, described an “ecological model of family functioning” and argued that all levels of this must be considered by teachers working with children with special needs. In the field of speech and language therapy, systems ecology has been cited to advocate liaison between home and school (Dockrell & Messer, 1999), and

interventions that address the needs of parents as well as their children (Bray, 2001).

Some justification for parent-based interventions has been presented in the practitioner literature based on pragmatic arguments. Both Porter and McKenzie (2000) on children with disabilities, and Gibbard (1998) in speech and language therapy, stated that professionals working in isolation could have only limited impact on a child's outcomes. Lindsay and Dockrell (2008) agreed, advocating an approach in which interventions were advised by a speech and language therapist and carried out by "individuals that a child interacts with on a daily basis" (Lindsay & Dockrell, 2008, p.135). While Lindsay and Dockrell stated that these individuals could be teachers, parents or other carers, Gibbard et al. (2004) argued that parents are the adults most frequently with their children, and so may be well-placed to provide frequent therapeutic input. Parents have also been described as appropriate providers of communication interventions owing to assumptions that they know their child well. In practitioner guidelines, parents have been described as "experts" on their own children (Royal College of Speech and Language Therapists, 2006, p. 243). Kaiser asserted that parents are "invested caregivers" (Kaiser, 1993, p. 63), and may therefore be better tuned in to their child than other adults. This may be supported by anecdotal observations from Lindsay and Dockrell (2008), who described parents of school-leavers with communication difficulties as identifying progress and barriers in communication, displaying sensitivity to their child's needs, and providing insights into their child's experience. However, this

may have been an idealised view of parents' skills; no research evidence for parental expertise was presented by these authors.

One rationale for parent-based intervention presented in the literature for which there is better support is the suggestion that parents shape the primary environment where their child communicates (Bray, Ross, & Todd, 1999), by providing language models and contingent responses to their child's communication (Kaiser, 1993). Studies have demonstrated associations between parents' communicative behaviours and those of their children. In a longitudinal study into the development of children with disabilities, use of maternal interaction skills such as sensitivity to cues and response to distress was associated with better communication skills in three-year-old children, and predicted better communication skills outcomes at age ten (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). Adults' child-directed speech has also been shown to influence the development of children's speech and language skills (see Clark, 2009 for a review of this topic). Further evidence comes from research into parent-based interventions themselves. For example, McDade and McCartan (1998), in a matched no-treatment control group comparison study, observed increased parent-child interactions following Hanen group interventions that were associated with increased child expressive language and could not be attributed to maturation alone. A case study by McCathren (2010) of parent-based intervention for a one year-old child and a mother with developmental difficulties, demonstrated associated outcomes of increased maternal use of facilitating strategies and increases in the child's communication attempts.

Unintended negative impacts of parent-based intervention for parents themselves have been raised by several authors. Whilst in speech and language therapy Bray (2001) argued that interventions should address the needs of parents as well as their children, various other writers of practitioner textbooks have identified tensions inherent in attempting to do this. For example, in their book on child disability Porter and McKenzie (2000) suggested that providing parents with a sense of control over their circumstances might improve how they cope with their child's disabilities. However, they argued that parents already cope to a degree and expressed concern that, when attempting to empower parents, professionals should avoid undermining them by suggesting otherwise. Parental stress has also been identified as a concern, and has been included as a secondary research parameter in several studies. For individual parent-based interventions, Fey et al. (2006), used the standardised Parenting Stress Index and found no significant change in stress levels following intervention. For parent-based intervention groups, Pennington, Thomson, James, Martin and McNally (2009) used the Parenting Sense of Competence Scale to assess changes in stress levels in their exploration of Hanen groups. They also found no significant change in parents' stress levels, but expressed doubts that their chosen instrument would identify all potential stresses. Hardy (1999), in a Ph.D. study of the National Autistic Society's EarlyBird programme, administered the Parenting Stress Index at four time points relative to the intervention groups, and found statistically significant reduction in stress between starting and finishing the course in both child and parent domains. While these quantitative methods provided no evidence that

parent-based interventions increase parental stress, there is some qualitative evidence that this may occur. For example, Goodhue et al. (2010) found that parents undergoing individually administered parent-based intervention for stammering reported difficulties fitting home interventions into the daily routine, and several studies in Watts Pappas and McLeod's (2009) review of the literature on parent-based allied health interventions yielded similar findings.

Views on the potential impact of parent-based interventions on parent-child relationships are also mixed. Cunningham and Davis (1985), and Lees and Urwin (1997) suggested possible negative impacts on the relationship. Cunningham and Davis suggested that emotional investment in their disabled child may mean that parents become more easily stressed or frustrated, and argued they should be left free to enjoy their child without added responsibility. Lees and Urwin argued that parent-based interventions may place a professional burden on the relationship. However Kaiser (1993) suggested that parent-based interventions may enhance the bond between parent and child as interaction and insight improve.

2.3 Group working

Group working is common to many disciplines; the literature includes sources written from the perspectives of managers, clinicians, and educators. This review drew on clinical and educational perspectives to explore the concept of group intervention more fully than was possible from speech and language therapy sources alone. The additional references used were Whitaker (2001) and Aveline (2003) from the field of clinical adult groups, Slavson (1958),

Behr (1997), Hornby (2000), and Campbell and Palm (2004) on parent education groups, and Nichols and Jenkinson (2006) on support groups.

Groups have been described in the literature as useful for providing several benefits simultaneously. For example, groups may provide supportive functions alongside more “educational” support; Campbell and Palm (2004) suggested that parent education groups allow parents to make new social networks while learning new skills. Referring to speech and language therapy groups, Backus and Beasley stated that "Within a group structure it is possible to be working on several different things at the same time..." (Backus & Beasley, 1951, p. 42). In the field of child disability, Cunningham and Davis (1985) described parent groups as primarily serving either training/education or support purposes, but stated that parents do not necessarily draw clear distinctions between these functions.

Parent education has been defined as “a process that involves the expansion of insights, understanding and attitudes and the acquisition of knowledge and skills about the development of both parents and of their children and the relationship between them” (National Parenting Education Network, 2011). Parent education groups have been described as providing a setting where parents "learn together in a mutually supportive atmosphere" (Hornby, 2000, p. 86).

Support groups have been described as providing “psychological or social support for those facing demanding or stressing circumstances” (Nichols & Jenkinson, 2006, p. 7). Their perceived purposes have included reducing isolation and validating members’ experiences through sharing (Wright, Sparks,

& O'Hair, 2008), and providing opportunities to express emotions and learn from other people's experiences to improve coping (Nichols & Jenkinson, 2006).

Nichols and Jenkinson argued that while support may occur in any group, organised support groups provide opportunities to meet others with the same problems and experiences, which are rarely available in group members' usual social circles. Parent support groups have been reported in the literature for parents of children with medical conditions such as Duchenne muscular dystrophy (Hodges & Dibb, 2010).

Group work has sometimes been advocated on the basis that groups cost less than individual interventions. For example, Cunningham and Davis asserted that parent groups are used because they are "more economical than working with individual families" (Cunningham & Davis, 1985, p. 119). However, in speech and language therapy the evidence about relative costs of group and individual interventions is limited and inconclusive. Gibbard et al. (2004) compared clinical outcomes and service provider costs per outcome for two parent-based intervention groups and for individual advice for children with delayed expressive language. They found that the groups generated better outcomes over the period of the study, and were slightly more expensive. Boyle, McCartney, Forbes and O'Hare (2007) compared group and individual direct interventions for children in primary school and found no significant difference in outcomes, with costs per primary outcome being lower for groups; in this latter study some costs were unavailable and were not included in calculations. Hence neither study provided evidence to justify or discount group working in speech and language therapy on economic grounds. Nor were costs

to parents themselves considered in either report, which Gibbard et al. identified as a limitation of their study. However, there has been more recent speculation about what some financial and organizational costs might be in terms of childcare, travel, time, and leave from work (Pennington et al., 2009).

Groups have been described in the literature as providing benefits not readily available in individual interventions. One impact of parent education groups observed by Slavson (1958) was that parents discovered their experience was not unique. Writers have asserted that this leads to several benefits. These include reduced feelings of isolation in both direct intervention (Whitaker, 2001) and parent groups (Behr, 1997), opportunities to see their own reactions to their situation as acceptable (Slavson, 1958; Whitaker, 2001) and their feelings as valid (Hornby, 2000), and encouragement to accept their situation and hope for change as they see it in others (Whitaker, 2001). Both Aveline on direct intervention groups (2003) and Slavson on parent groups (1958) observed that group members can benefit from “reduction of ego load”; as group members discover that their situation is not unique, they become less burdened by their own reactions and feelings such as guilt.

There is some evidence in the literature for groups providing reduction of isolation and an experience of validation. Hodges and Dibb (2010) interviewed parents of boys with muscular dystrophy about parent support groups and found that validation of feelings was perceived as helpful by parents. Hornby (2000) argued that validation of feelings through sharing similar experiences enabled parents to perceive a setting as a safe place to explore difficult issues. This was supported by a finding from Beresford (1994). She conducted in-depth

interviews with twenty parents exploring their experiences of caring for a child with a disability or chronic illness; the parents reported that they were more likely to disclose negative feelings and situations to less familiar parents who were also dealing with a disabled child, rather than to parents they already knew.

Another observation from practitioners contributing to the literature is that groups provide participants with access to a wider range of experiences and coping strategies (Aveline, 2003). Nichols and Jenkinson refer to a “richness of information” (Nichols & Jenkinson, 2006, p. 20) available in groups when compared to individual sessions, and Whitaker (2001) suggested that this exposes group members to new options for their behaviour choices. Hornby (2000) described parent education groups as exposing parents to a range of ideas and strategies; Behr described parents accessing “the combined expertise of the other parents in the group” (Behr, 1997 p.124). In her speech and language therapy parent-based intervention groups, Gibbard (1998) observed that group discussion and formal group activities tapped into a variety of parental experience, leading parents to develop flexibility in working with their child. She also observed that participants offered each other specific ideas and suggestions to enhance their children’s communication.

Some writers have observed that group members may value each others’ views more than professional opinions. Aveline (2003) suggested that, in clinical therapy groups, support and challenge from peers is seen by group members as more trustworthy than professional comments. Likewise Hornby (2000) reported that parents can be more responsive to solutions suggested by

other parents than by professionals. Girolametto and Weitzman (2009) reported an example supporting these suggestions. They described a family who had previously resisted the use of signing with their child when it was suggested by a speech and language therapist; the parents introduced the strategy when they encountered other parents using signing successfully. Other writers have described mutual support in parent groups leading to increased recognition of, and confidence in, members' own parenting skills (see Behr, 1997; Hornby, 2000). Behr (1997), observed that in groups parents may discover that professionals are not their only sources of help.

Groups have been shown to provide opportunities for comparison. Hodges and Dibb (2010) asked parents what they found helpful or unhelpful about support groups. Although they expressed embarrassment about it, parents identified comparison as a helpful process. They described upward comparisons with parents, or children, doing better than they were as inspiring, and downward comparisons with others worse off as prompting gratitude about their own situation. Parents in this study also reported negative responses to comparison; they coped with this by making comparisons on different, more favourable dimensions to increase positive feelings.

Several commentators have suggested that group interventions with peers may be less intimidating than individual interventions with professionals. Interaction with professionals can be difficult; Beresford's parent interviewees viewed dealing with professionals as a significant stressor (Beresford, 1994). In speech and language therapy, professionals have been described as "both helpful and threatening" (Bray, 2002, p. 117). Bray also suggested that,

compared to individual interventions, group members may experience less pressure from professionals.

2.4 Research into parents' views and experiences of speech and language therapy

In speech and language therapy, exploration of parents' experiences has been somewhat limited. In a 2009 review of research into parents' views of intervention by allied health practitioners (Watts Pappas & McLeod, 2009), thirty-eight studies published between 1981 and 2006 were identified. Twenty-nine of these related to physiotherapy, occupational therapy or multidisciplinary teams. Eight out of the nine studies into speech and language therapy had been published since 2000 (Watts Pappas & McLeod, 2009). In this literature review, a similar pattern emerged. Parents have been consulted on various issues, but they have often been treated as sources providing discrete items of information considered relevant by researchers. Fewer studies have sought to discover what is most relevant to parents by allowing them to express their own priorities. Four studies were identified in the literature search which explored parents' experiences of parent-based intervention in this way; these will be considered in the context of how parental perceptions have been accessed more generally.

As sources of information on their own children, parents have been asked to provide both qualitative and quantitative data. For example, a study by Brady, Skinner, Roberts and Hennon (2006) used semi-structured parent interviews to obtain qualitative descriptions of communication in children with

Fragile X syndrome, as part of a broader longitudinal study on the children and their families. Researchers have used parents' responses on observation scales to measure behavioural outcomes in children following intervention (for example, Boyle et al., 2007). Parents have been informants in service delivery evaluations; this has commonly been through completing satisfaction surveys (for example Gaines & Gaboury, 2004; Girolametto et al., 1986), although qualitative questionnaires have also been used to gather parent perspectives of educational provision for children with specific speech and language impairments (Lindsay & Dockrell, 2004). The investigation of a single dimension of parents' own experiences of speech and language therapy has sometimes been included within wider studies; this was the case for the measurements of parental stress described in section 2.2 above.

Several studies reported in the literature included wider exploration of parents' own understandings and experiences of aspects of speech and language therapy, but related to direct interventions with the child rather than the parent. Some of these were embedded in two larger projects undertaken by Glogowska and colleagues (Glogowska, 2002; Glogowska & Campbell, 2000; Glogowska, Roulstone, Enderby, Peters, & Campbell, 2001) and by Boyle et al. (2007). During a randomised controlled trial, Glogowska and Campbell (Glogowska, 2002; Glogowska & Campbell, 2000) explored the views of eighteen parents of pre-school children about their child's communication difficulties and their experience of individual direct speech and language therapy intervention. They found that parents saw themselves as assisting speech and language therapists but expecting to be instructed in what to do by

“experts” (Glogowska, 2002). They also viewed intervention as costly and weighed costs against benefits; if the costs were too high they became disengaged from intervention (Glogowska & Campbell, 2000). Glogowska et al. (2001) interviewed a second sample of parents about their experience of taking part in research. They found that parents viewed taking part in research as gaining an advantage for their child. Boyle et al., in their comparison of group and individual interventions asked parents about their child’s outcomes; they also gathered parents’ views on the intervention itself, and their experience of the research project. Regarding this latter study, Boyle et al. described their findings as comparing direct and indirect interventions; however, the “indirect” interventions they described were administered by trained speech and language therapy assistants, as opposed to parents or teachers.

Other researchers have explored parents’ perceptions of child-based speech and language therapy interventions and their child’s needs at key points in their child’s therapy. For example, Marshall and Goldbart (2008) used semi-structured interviews to explore the views of parents whose children were beginning to use Augmentative and Alternative Communication (AAC). Marshall et al. (2007) used unstructured interviews with twenty parents of children recently referred for speech and language therapy to explore their perceptions of their child’s difficulties, factors influencing language development and delay, and speech and language therapy itself. This study used grounded theory approaches to develop descriptive models of the beliefs of both parents and speech and language therapists, who were also interviewed, about language development and language delay (Marshall et al., 2007). The researchers

identified that both parents and speech and language therapists saw internal and external factors as significant to language development and delay, but the two groups differed in terms of the factors they identified within these categories. They also differed regarding their views of intervention, with parents tending to expect a more directive approach than therapists considered appropriate.

Of the four studies identified as exploring parent-based intervention from a parent-led perspective, two related to individually administered intervention and two related to parent-based intervention groups. Studies by Hayhow (2009) and Goodhue et al. (2010) explored parents' experiences of the Lidcombe Program (Onslow, Packman, & Harrison, 2003), an individually administered parent-based intervention in which parents are trained to use behavioural techniques to reduce stammering. Hayhow used an inductive approach to explore the perceptions of parents of fourteen children in the programme, using semi-structured parent interviews carried out once during intervention, with six parents being re-interviewed to identify changes over time. Goodhue et al. studied changing perceptions during intervention by conducting repeated semi-structured interviews with sixteen mothers during treatment, initially face-to-face and subsequently by telephone. Of the remaining two studies, that by Lyons et al. (2010) sought parents' views regarding a treatment package which mainly used direct approaches but included instruction to parents; what was not clear from their report was the level of parent-based input. The sample size was small; eight parents attended the pre-treatment focus group and three attended post-treatment. The finding relevant to parent-based interaction was that

parents did not expect their interactions to be a focus for intervention; Lyons et al. concluded that expectations and roles should be clarified prior to therapy.

The most informative study regarding parents' experiences of parent-based intervention groups was reported by Baxendale, Frankham and Hesketh (2001). They compared "Hanen" parent-based intervention groups with direct therapy. As well as comparing outcome measures for the children in the study, satisfaction questionnaires requesting qualitative information were completed by thirty-seven parent participants. In-depth interviews were also conducted with eighteen of these parents, ten from Hanen groups and eight from direct intervention, to explore differences between the two groups in their expectations of treatment, their view of the therapy they received, and the impact of the interventions. Baxendale et al. found that initially parents in the Hanen groups expected their child to receive direct treatment, and that through attending the group parents came to view parent-based interventions as preferable. Following intervention, parents saw themselves as able to help their child, having "fine-tuned" their interactions, but also saw development as something their child ultimately had to do. They identified assessing videos in a group, and role-play activities, as effective learning experiences, although they found role-play stressful. Most parents valued meeting other parents as part of the group. Baxendale et al. also noted that parents used the frameworks introduced in intervention to talk about their children during research interviews.

2.5 Methods used to explore parents' views in speech and language therapy research

The methods used to investigate parents' perceptions varied with the topic being studied. Where parents provided information to evaluate their child's outcomes, a range of scales were used; for example, Boyle et al. (2007) used parents' responses to observation scales and Likert scale-based questionnaires. Gaines and Gaboury (2004) used retrospective review of satisfaction/dissatisfaction survey results from parents attending their course over a three year period alongside therapists' outcome measures for the children. Rating scales were also used to investigate satisfaction (Girolametto et al., 1986) and levels of parental stress (Pennington et al., 2009). Qualitative questionnaires were used to investigate parents' views of service delivery (Boyle et al., 2007; Lindsay & Dockrell, 2004).

In using these methods, the researchers restricted their potential findings to predetermined categories, potentially preventing a full reflection of respondents' experiences. Some researchers attempted to address this through providing parents with some space for additional comments on forms (Boyle et al., 2007), or carrying out semi-structured interviews with some participants (Lindsay & Dockrell, 2004). Recent studies have taken other approaches designed to increase correspondence between the data collected and parents' concerns. In child outcome investigations, questionnaires requiring qualitative responses were used to explore parents' expectations and observations of their child before and after intervention as an initial step towards identifying appropriate indicators for functional outcomes (Thomas-Stonell, Oddson,

Robertson, & Rosenbaum, 2009). In service delivery evaluations, focus groups with parents were used to inform the design of a questionnaire which was then completed by a further 103 parents to evaluate parents' views of speech and language therapy services for school aged children with intellectual disabilities (Carroll, 2010). Another study employed parent interviews to revisit and clarify information from a previous questionnaire-based study of access to speech and language therapy in Victoria and New South Wales (McAllister, McCormack, McLeod, & Harrison, 2011).

Studies which aimed to explore parents' own experiences in more detail used qualitative approaches such as interviews (Baxendale et al., 2001; Glogowska & Campbell, 2000; Glogowska et al., 2001; Goodhue et al., 2010; Hayhow, 2009; Marshall & Goldbart, 2008; Marshall et al., 2007) and focus groups (Boyle et al., 2007; Lyons et al., 2010). The study by Lyons et al. was a piece of action research; focus groups were held before and after treatment to explore parents expectations and experiences of the intervention, and changes were made in the organisation of the intervention based on data from the first focus group. Interviews were variously described as semi-structured or unstructured; however, the limited detail reported prevented assessment of the accuracy of these descriptions in some cases. Some interviews were used in association with grounded theory methods (Hayhow, 2009; Marshall et al., 2007).

The use of grounded theory approaches in speech and language therapy research appears limited. Skeat and Perry, who published a paper outlining methodological issues and reviewing prior studies in 2008, speculate that this is

due to the time-consuming nature of grounded theory methods. Although they argued that such research rarely produced grounded theories in speech and language therapy, some studies have in fact proposed hypotheses, or models grounded in their data that provide tentative hypotheses, open to further investigation (Marshall et al., 2007). Skeat and Perry themselves presented a theory about the use of outcome measures by speech and language therapists (Skeat & Perry, 2007). Other studies have presented a substantive theory about elements of the therapeutic relationship grounded in interviews of adults with acquired communication and swallowing disorders (Fourie, 2009), and grounded descriptions of other topics unrelated to the present study. Studies using grounded theory approaches to investigate parents views have produced grounded descriptions of experience of individual parent-based intervention (Hayhow, 2009) and parents' views of quality of life for children with communication difficulties (Markham & Dean, 2006).

2.6 Theoretical concepts

During data analysis, it became apparent that issues of parental adaptation to dealing with a child with communication difficulties and parental empowerment were significant to participants. A systematic search of the literature (see Appendix A) revealed no studies of these areas directly related to speech and language therapy. However, grounded theory methods can generate reviews of the literature across disciplines (Charmaz, 2006), and a wider search located sources in the fields of childhood disability and chronic illness. These are presented below.

2.6.1 Parental adaptation and coping

Parents' discovery that their child has a special need has been described as a "crisis" for families, to which they and their social networks need to adapt over time (Appleton & Minchom, 1991, p. 36). Successful parental adaptation has been described as developing appropriate coping skills (Beresford, 1994), and as a process of acquiring knowledge, skills, and resources, resulting in mastery of, and increased autonomy in dealing with, the child's situation (Clawson, 1996).

One model of the adaptation process for parents of a child with a disability was developed by Andereg, Vergason, and Smith (1992). Starting from a premise of grief as an appropriate response to having a child with a disability, Andereg et al. described an ongoing cycle of confronting, adjusting, and adapting to circumstances, and identified emotions and psychological tasks associated with each stage. In this model, confronting was associated with emotions such as guilt, and required parents to explore and acknowledge their situation. Adjusting required parents to accept the reality of their situation and develop a sense of power, and adapting required alteration of expectations, realistic planning and appropriate changes in behaviours.

Another description of the adaptive process was provided by Canam (1993). Canam described adaptation in terms of learning to cope with a child's chronic condition, and identified a number of "adaptive tasks" which parents face (Canam, 1993, p. 46). These tasks included accepting the child's condition, managing the condition on a day-to-day basis, dealing with stress, and educating others about the child's condition. Canam reviewed the literature

for processes identified as supporting some of these tasks; she referred to these as coping strategies. For example, coping strategies of developing control and opportunities for comparison were identified as helpful to meet the adaptive task of accepting the child's condition. Obtaining accurate information and understanding of the condition were reported to facilitate managing the condition on a day-to-day basis, and developing problem-solving skills was found to be helpful for dealing with stress (Canam, 1993).

Coping strategies and skills were also explored by Beresford (1994) in her interviews of parents with severely disabled or chronically ill children. Beresford found a wide range of coping strategies reported by parents. Helpful strategies included accepting the situation, pre-empting problems through day-to-day management and sensitisation to the child's early warning signs, understanding the child's perspective, venting emotional distress, comparing themselves with others worse off, problem solving, and taking control of the situation.

2.6.2 Empowerment (Gibson, 1995)

Parents' ability to use resources adequately has been thought to depend on their views of themselves as effective (Heiman, 2002) and empowered. One model of empowerment was developed by Gibson (1995), who studied the process by which mothers of children with severe neurological problems became empowered to participate in decision-making about their child. Gibson pointed out that, by their nature, processes cannot be captured by a single measure, so she used repeated interviews, observations, and memo writing to develop her model of the process of empowerment in her participants. Gibson

described empowerment as a learning process, with positive consequences of self-development and mastery of their situation. Her model showed an iterative four-stage process of “discovering reality”, “critical reflection”, “taking charge”, and “holding on”. She described each stage as being associated with certain tasks or processes. “Discovering reality” involved emotional reactions to diagnosis and seeking information, with high associated levels of frustration. During “critical reflection”, parents engaged in comparison and developed awareness of their own strengths and insight into their child, leading to increased confidence in their own abilities. Increased confidence led to mothers “taking charge”; they reduced their reliance on external, professional authority and took on responsibility themselves, learning how to deal with their situation and becoming advocates for their child. As the mothers persisted in these roles (“holding on”) Gibson observed knowledge, skills (including decision-making), and confidence to communicate their insights to others.

2.7 Conclusion

In this chapter, literature relevant to the current study has been reviewed, and literature on key concepts identified during data analysis has been presented. Sources outside the field of speech and language therapy have been included in some cases.

Investigation of parents’ perspectives in speech and language therapy is a developing research area. Parents have been used as sources of information about their child, and about discrete elements of their experience such as stress. They have contributed to service delivery evaluations through measures

of satisfaction. Some studies have sought to understand their perspectives in more detail; researchers have explored parents' understandings of their children's needs, their expectations and perceptions of speech and language therapy, and their experiences of taking part in research.

Most studies exploring parents' experiences of speech and language therapy interventions have focused on direct interventions or individually administered parent-based interventions. Of the two studies involving parent-based intervention groups, one investigated a mixed intervention that included direct treatment of the child; the other focused on comparing direct and parent-based methods. Both studies yielded findings on some details of parents' experiences and perceptions. However, a systematic search of the literature identified no studies that explored parents' experiences of speech and language therapy parent-based intervention groups from a broad perspective that allowed parents' own priorities to be identified. This was the aim of the present study; the research strategy, study design and methods adopted to carry out the study are presented in Chapter 3.

Chapter 3

Methodology

3.1 Introduction

The aim of this study was to conduct a preliminary exploration of parents' and carers' experiences of attending parent-based intervention groups, by investigating their understandings of the purposes and nature of the groups they had attended, and developing a preliminary theoretical understanding of their experience. In this chapter, the research strategy and study design adopted and the methods used to address these aims are described. Ethical considerations and research quality issues relating to the study are discussed throughout the chapter, and the management of the research project is summarised.

The choice of qualitative or quantitative research strategy, study design framework, and methods of data generation and analysis, are influenced by ontological and epistemological positions as well as by the research question being posed. Ontology concerns philosophical positions regarding the nature of reality. Two possible positions, when considering the reality of social entities such as groups, are objectivism and constructionism (Bryman, 2004). The objectivist position views social entities as externally structured, relatively stable, and observable by others. However, the constructionist position views them as being negotiated and modified internally by individuals and their interactions. The research question in this study was not concerned with observable external structures, but with individual parents' internal

constructions about what happened and what it meant to them. Consequently, a constructionist ontological position informed decision-making in this study, particularly in the light of evidence suggesting that parents' and clinicians' constructions can differ with respect to the meanings of speech and language therapy intervention (Marshall et al., 2007).

Epistemology addresses the nature of knowledge and how it is obtained. Contrasting epistemological positions include positivism, realism, and interpretivism (Bryman, 2004). Positivist and realist positions are associated with objectivist ontology. Bryman has described both positivism and realism as positions that hold that a relatively accurate description of an external reality is possible, provided a researcher uses sufficiently objective measures. However, realism is somewhat nuanced. Critical realist positions regard some aspects of reality as not directly observable, admitting a need for researchers to use their own descriptions, and considering these as approximations rather than absolutely corresponding with reality. A realist position has been described as compatible with investigating reported perceptions (Finlay, 2006; Robson, 2011). In contrast, interpretivist positions are compatible with constructionist ontology, holding that the participant's knowledge is subjective, being constructed by each individual as they interpret their experiences. Hence, the researcher attempts to understand the meanings attributed to a phenomenon by each participant. As parents' own understandings were the subject of the current study, the epistemological position chosen was interpretivism. Interpretivism also allows for "surprising" findings (Bryman, 2004), which is helpful in an exploratory study open to new insights.

3.2 Research strategy

The aim of this study was to explore relatively “uncharted territory”, seeking understandings that were significant to the participants without imposing limits based on the preconceptions or prior definitions of the researcher. To achieve this, a research strategy was required that allowed wide ranging exploration of the topic area and use of an inductive approach to build up theory from the research findings. Quantitative research strategies were unsuitable for this. They are associated with an objectivist ontology and positivist epistemology and focus on carefully isolated and specified dimensions in a field of enquiry (Rudestam & Newton, 2007); they are generally used for a deductive approach in which research questions are defined by pre-existing theory (Bryman, 2004). Quantitative strategies have been used to evaluate some dimensions of parents’ experiences in parent-based intervention groups (e.g. Fey et al., 2006); however in the present study they would have focused too narrowly by specifying and thereby limiting the dimensions to be covered.

Qualitative strategies, on the other hand, are associated with constructionist ontology and interpretivist epistemology; they were selected for the current research question, as they allow participants to provide their perspectives on unobservable phenomena, and are designed to study a phenomenon in its entirety (Rudestam & Newton, 2007). Miles and Huberman (1994) describe qualitative approaches as helpful for eliciting participants’ meanings. The emphasis in qualitative research is on gathering rich data (Denscombe, 2003) from participants themselves, using an inductive approach (Charmaz, 2006) to build up understanding of their most salient concerns.

Hence, qualitative and inductive strategies were selected to underpin the study design.

3.3 Study design

The study was a small exploratory cross-sectional study using a flexible design. A cross-sectional design was selected to gather the widest possible range of perspectives from parents in a limited time. Flexible designs have been described by Robson (2002) as systematic, yet developing or evolving as a study proceeds; hence flexible designs enable balance between flexibility to explore issues emerging from the data and the need to maintain organisation and rigour (Bowling, 2002), and ultimately complete the project.

Grounded theory approaches (Charmaz, 2006; Glaser & Strauss, 1967) were selected to inform the developing design, because grounded theory frameworks provided structured, systematic approaches to data sampling, data generation, and analysis (Charmaz, 2006), aiding completion of a useful study within limited resources (Charmaz, 2006; Skeat & Perry, 2008) for an inexperienced researcher. Grounded theory approaches were also consistent with the exploratory nature of the research question, inductive and qualitative strategies, and constructionist and interpretivist positions. Grounded theory methods have been advocated for research into speech and language therapy practice because they focus attention on participants' concerns and on human interactions, which underpin therapy (Skeat & Perry, 2008).

Two qualitative data generation methods were considered for this study. These were interviews and focus groups, both of which have been used to

gather data from parents and carers in speech and language therapy (Glogowska & Campbell, 2000; Lyons et al., 2010; Marshall & Goldbart, 2008). Whilst focus groups have some potential advantages, such as economy, generation of large amounts of data, and encouraging participation (Robson, 2002), some researchers have noted that group cohesion may lead responses to reflect a consensual and overly positive view (Girolametto, Tannock, & Siegel, 1993) and the topics covered may be limited (Robson, 2002). For the current study, where a range of individuals' views were sought to open up a topic area, this focus on the "collective view" (Denscombe, 2003, p. 169) was a significant disadvantage. Instead, interviews were selected because the participant's "story" could be better placed in context (Purtillo & Haddad, 2002) and would not be constrained by the presence of other participants (Charmaz, 2006; Maykut & Morehouse, 1994). There were also practical advantages. For example, data obtained from interviews have been described as easier to manage than data obtained through focus groups (Robson, 2002), and arranging individual interviews was simpler than co-ordinating groups.

3.4 Ethics and trustworthiness of research

When planning and executing research, it is necessary to ensure it is of high quality, and carried out ethically. This study involved carers of National Health Service users. Consequently, ethical approval was required from North Staffordshire Research Ethics Committee, Shropshire County NHS Primary Care Trust, and Telford and Wrekin NHS Primary Care Trust. Copies of letters confirming approval from these organisations are presented in Appendix B.

While designing the study, ethical issues of confidentiality, informed consent, and avoidance of harm were addressed. Records of the research process were required for an audit trail (Denscombe, 2007), so data management strategies were key to preserving confidentiality. Personal data obtained during this study were handled in accordance with the principles of the Data Protection Act (see Information Commissioner's Office, 2011). Minimal contact details were obtained, and were stored in a separate secure location from other records. Participants were given an anonymised identifier; the key to this was retained securely. Data were rendered anonymous during transcription, and specific diagnostic information was not linked to specific quotations used in reporting, as these might identify particular parents. Audio recordings, anonymised transcripts and correspondence were placed in locked storage. Electronically stored data, whether identifiable or anonymised, were held on an encrypted password protected device. Arrangements were made to prevent backup to a central NHS server, as this would have prevented destruction of records after the ten years of storage required by University regulations.

The speech and language therapists dealing with the sample population were “blinded” to the identity of parents volunteering for the study both for ethical and methodological reasons. The children of potential recruits were receiving ongoing care; this made parents vulnerable in several ways. In terms of ethics, if the child’s clinician knew who had volunteered there was a risk that parents would feel obliged to participate. At the same time, previous research suggested that parents could mistakenly believe that their participation would

lead to enhanced treatment for their child (Glogowska et al., 2001). In both cases, this created a risk of coercive influence. In addition, the sample population attending groups over the course of the study was limited in size. Clinicians who knew volunteers' identities might be able to identify participants from the final report.

In terms of bias, participants could feel constrained about divulging information to the researcher if they believed that their clinician was aware of their participation. There was also a risk that if clinicians were aware a parent had volunteered for the study this could influence the information they gave to that individual during subsequent interventions, altering parents' retrospective perceptions of the groups being studied.

The National Research Ethics Service required copies of parents' signed consent forms to be placed in their children's speech and language therapy case-notes. However, this had implications for breaching confidentiality because the child's clinician would access the notes. The researcher therefore proposed to the Committee that consent forms be placed in the notes after a delay of five years, or at discharge if earlier, and the Research Ethics Committee approved this.

Informed consent was viewed as an ongoing process (Miller & Bell, 2002) and was addressed during several phases of the study in addition to signing the consent form. At recruitment, completion of an interest form was considered as consent to be contacted by telephone about participating in the research at a later stage. At this telephone contact, volunteers were explicitly asked whether they were still prepared to be interviewed, on the assumption

that their views or circumstances might have changed. Separate signed consent forms for the interview and for use of quotations were required by the Research Ethics Committee. Finally, transcript checking provided participants with a final opportunity to be informed about the process in which they had been involved, and to acknowledge their ownership of the views they had expressed (Oliver, 2003).

When considering potential harm to participants, loss of time, possible financial costs, invasion of privacy, and potential for distress were identified. To minimise loss of time and financial costs, home visits were offered for data generation and postage for return of interest forms and transcripts was paid by the researcher.

Some invasion of privacy, albeit with consent, was an inevitable consequence of participating in the study, and since home based interviewing might increase this, local clinics were offered as an alternative venue for data generation. Confidentiality safeguards have been described above.

In terms of potential for distress, there was a possibility that discussing the groups could raise concerns or worries that the participant found painful. Strategies to address this, including supportive listening, directing to sources of support, and interruption or termination of interviews, were identified prior to study commencement. Although there was no planned benefit of the study, it was recognised that there was also a possibility that reflecting on intervention could be beneficial and an opportunity for clarification. It was therefore decided that answering participants' questions be included in the study protocol.

Within quantitative research strategies, quality issues are addressed by emphasising reliability and validity. Various adaptations and redefinitions of these parameters have been suggested within qualitative research (Bryman, 2004) because the original use of these terms reflects their basis in objectivist paradigms. The concepts of validity and reliability arose from a position holding that an objective external reality can be apprehended; consequently, research is valid insofar as it reflects that reality accurately, and reliable insofar as the information obtained can be confirmed through repeated measures. These definitions do not correspond with constructionist and interpretivist positions, because reality is seen as constructed from the meanings held by individuals, and as subject to change.

The concept of trustworthiness of research (Lincoln & Guba, 1985) was used as the starting point for ensuring quality in this study. Lincoln and Guba described establishing trustworthiness in qualitative research in terms of credibility, or the degree to which the researcher's report reflects the participant's perceptions, transferability of the findings to other situations, dependability or rigour of the research process, and confirmability, which they related to objectivity of findings and interpretations. While they drew parallels between these criteria and those of validity, reliability and objectivity, in a qualitative study such as the present one, there was a greater emphasis on validity of findings, and researcher objectivity was considered in terms of balancing involvement and detachment (Elias, 1998).

A number of the methods Lincoln and Guba (1985) suggested for addressing their criteria were inappropriate or impractical for a small exploratory

study. For example, triangulation and peer debriefing were suggested for addressing issues of credibility; triangulation was not attempted as it implied a realist epistemology in which findings can be verified through different measurements, and opportunities for peer debriefing were limited. However, other methods were more appropriate and feasible. Detailed records were made of each step in the study, including data generation and analysis; this is useful in providing a clear “audit trail” to demonstrate dependability of the research process and confirmability of the final product. A full description of methods and of the study participants contributes to these aspects of trustworthiness, and is helpful in providing information for those who may need to consider transferability of the study findings to other settings (Lincoln & Guba, 1985). Raw data was also retained for the same reasons. Other methods of maximising validity and trustworthiness of the research are included in the description of the study methods presented in section 3.5.

A particular issue for both ethics and trustworthiness in the current study was conflict of interests. The researcher was a clinician undertaking research in the workplace. While clinical and workplace knowledge could be helpful in understanding the context of the study and obtaining access to the sample population, this dual role posed several potential risks. For example, workplace relationships may lead to attempts to influence research (High & Montague, 2006); this risk was reduced by independent funding and external supervision.

Inclusion of the researcher’s own clinical caseload in the study was particularly high-risk. Parents could feel coerced into participating, or might provide biased, circumscribed or expanded information. In coding and analysis,

clinical “insight” on the researcher’s part could indicate excessive involvement as a clinician rather than the balance of insight and detachment appropriate to research (Elias, 1998). For both researcher and participant, a pre-existing parent-clinician relationship could alter the nature of a research interview (Graves, 2007). For these reasons, the researcher’s own caseload was excluded from the study.

However, the researcher retained the perspective of a clinician, which posed a risk in respect of researcher objectivity, and the possibility of interference in the findings from “inquirer values” (Lincoln & Guba, 1985, p. 293). Methods used to address this risk included the use of researcher identity memos (Maxwell, 2005). These were written prior to the study to alert the researcher to possible biases, with the aim of enabling “bracketing” (setting aside) of clinical and personal preconceptions. Supervision was also useful in keeping the researcher’s awareness of these issues to the fore. Interview recordings and transcripts were checked for bias in researcher questioning and responses during the interview (Denscombe, 2003; Robson, 2002) between each data generation cycle. The iterative method of using data generation cycles to inform further cycles, rather than generating all the data before analysis, built reflective pauses into the coding process that helped ensure appropriate levels of detachment (Glogowska & Campbell, 2000). Finally, contact was limited to a single interview, as longer involvement could have increased the likelihood of intrusion of the clinician role (Robson, 2011).

3.5 Study methods

3.5.1 Sampling and recruitment

The sample population included all parents/carers who completed a parent-based intervention group delivered by paediatric speech and language therapists working for the local NHS Trust during the duration of the study. All childhood communication difficulties addressed by parent groups were included with the exception of stammering, because this was the caseload managed by the researcher in a clinical role.

The sample was limited to parents who had completed groups because these individuals had experienced all or most of the group process, and so would have more complete and possibly more detailed perceptions of the nature and purposes of the groups. It also enabled exclusion of the perspectives of parents who had declined, opted out, or been unable to complete courses, whose experiences were different and could have reduced the likelihood of data saturation within the time available for the current study.

The planned sampling method was to recruit a “pool” of volunteers from the sample population to act as a sampling frame, and to select participants from the sampling frame using purposive grounded theory techniques (Charmaz, 2006). The aims were to sample initially for maximum variation between groups attended to open up the field of enquiry and subsequently, following identification of theoretical categories from analysis of the data, to use theoretical sampling (Charmaz, 2006). Theoretical sampling involves seeking study participants who can shed light on the detail and limits of the categories identified; for example, “negative cases” whose experience could

challenge or contradict the developing categories, are sought in order to explore the resilience and/or limits of the researcher's ideas (Robson, 2002) and ensure credibility (Lincoln & Guba, 1985).

Choice of sample size was influenced by the need to balance opportunities for data saturation against the practical constraints of study size (Maykut & Morehouse, 1994). In this case, a sample size of twelve participants was planned, as likely to generate sufficient data and the possibility of data saturation, balanced against the time limits of a Masters' dissertation and possible disruption to local services. However, it was acknowledged during planning that due to inherent tension between grounded theory requirements to follow the participants' lead in developing theory (Charmaz, 2006) and the time, resource, and scoping constraints of the dissertation, data generation could be incomplete, as observed by Robson (2002). In the event, ten volunteers were recruited within the time available. Consequently, all volunteers were invited for interviews, and the study sample was in effect a convenience sample of ten participants.

Speech and language therapists working in the Trust were informed of the study at a team meeting, and provided with a Therapist Information Sheet (see Appendix C). Therapists were encouraged to inform the researcher of groups meeting the criteria of providing parent sessions with a focus on indirect intervention. Recruitment was then carried out through the researcher meeting parent groups for approximately twenty minutes during the final session of parent-based intervention courses. The final session was chosen in order to ensure participants met the criterion of having completed a course, and to

minimise any alteration in the parents' attitudes to or participation in the group due to earlier awareness of the research. Recruitment occurred in the absence of the professionals delivering the interventions, to reduce the possibilities of bias and perceived coercion and to facilitate confidentiality as described in section 3.4. Thirteen parent-based intervention groups ranging in size between three and approximately sixteen parents were visited for recruitment over a seventeen-month period; these groups provided interventions for early communication skills development, expressive language development, speech sound development, Makaton training, cleft lip and/or palate, and autism.

During recruitment meetings, Participant Information Sheets (see Appendix D) were distributed. The research was also described verbally, to allow for differing literacy levels, and questions were invited. The researcher explained the absence of the clinician and emphasised that the study was separate from the group course and any future treatment. In order to reduce a possible sense of coercion, group members were asked to think over the information they had been given at home, and stamped addressed envelopes and "Interest forms" (see Appendix D) were distributed so parents could express interest in the study after reflection. However, if group members wished to complete the form immediately this was also accepted, because consultation prior to the study with colleagues and others who were parents suggested that some prospective participants would prefer this.

The Participant Information Sheet, Interest form and consent forms were checked for literacy levels using an online readability index calculator (Krantz, 2005b) which used an algorithm from the Flesch-Kincaid scales. While such

scales do not measure “understandability” (Krantz, 2005a), they do provide an indication of the complexity of the language used. The forms were also reviewed by an individual with personal experience of speech and language therapy parent-based intervention groups, known to the researcher in a non-professional capacity. The Participant Information Sheet in particular was substantially altered as a direct result of this consultation.

Recruitment continued throughout the study, in order to sample from as wide a range of groups as possible. Initially ongoing recruitment was also planned to allow targeted recruitment for theoretical sampling (Charmaz, 2006) and negative case sampling to counteract bias (Robson, 2011). However, the limited number of volunteers and consequent change to convenience sampling made this second purpose redundant.

3.5.2 Data generation

Data from this study were viewed as being generated jointly by the participant and researcher, rather than being collected. This corresponded to the constructionist and interpretivist positions that informed the research, and was also influenced by the selection of grounded theory approaches and the choice of interviews for data gathering. Interviews have been described as collecting ideas rather than data (Oppenheim, 1992), and the interview process involves interaction between interviewer and interviewee, collaborating to explore these ideas (Oakley, 1981). This is followed by the development of codes and categories by the researcher (Charmaz, 2006), as the ideas collected are interpreted (Denscombe, 2007). Joint participation in developing

data is reflected by Oliver (2003), who argued that participants “own” the raw data that they provide, with the researcher “owning” the analysed data.

Interviews were structured as loosely as possible to allow participants to introduce information outside the researcher’s preconceived ideas.

Nevertheless, a carefully planned interview was also necessary (Denscombe, 2007) to ensure that data generated was both sufficient to address the research question and rich in detail (Charmaz, 2006). For example, it was important that participant’s answers were guided away from a tendency towards a particular style of answer, for example often agreeing with the interviewer, or a bias towards providing socially desirable answers (Bowling, 2002), which might not accurately reflect the participants’ experiences and constructs (Robson, 2002), thereby reducing credibility (Lincoln & Guba, 1985). It was also important to plan the interview to avoid the use of directive questions by the interviewer which would limit the data obtained (Charmaz, 2006).

Since Denscombe (2007) has pointed out that semi structured and unstructured interviews exist on a continuum and the level of structure can vary during an interview, an interview guide containing possible questions and probes (Charmaz, 2006) was developed to provide a flexible framework for the researcher to use when necessary. The guide contained introductory comments with discussion of the recording equipment (Maykut & Morehouse, 1994), and brief factual questions to elicit contextual information and “break the ice” (Marshall & Goldbart, 2008). These were followed by questions developed using methods described by Wengraf (2001). “Central research questions” were identified from the initial research question; theory questions were developed

from these, and interview questions were developed from the theory questions. The wording of the interview questions was then considered to identify and improve the narrative form responses were likely to take. Finally, the revised interview questions were mapped back onto both theory and central research questions to ensure no loss of relevance (Wengraf, 2001), and possible prompts, probes and checks were added (Denscombe, 2007). Each stage of this process was recorded and stored as part of the audit trail. The initial interview guide is shown in Appendix E.

Following each interview, the interview guide was reviewed and minor changes made to refine questions and probes in the light of participant responses, in line with grounded theory methods (Charmaz, 2006). Additional questions were also introduced as new objectives emerged. For example, it became apparent after four interviews that most parent-based interventions being discussed included one-to-one sessions, which had a bearing on parents' perceptions of the groups. Thus an emerging objective (Charmaz, 2006) was to explore the relationship and distinctions between group and one-to-one sessions, and Wengraf's method was used to generate three additional interview questions addressing this (Wengraf, 2001).

Each participant was interviewed once during the study. The researcher first telephoned a volunteer from the sampling frame to check whether they were still available for interview, before arranging an interview appointment. Participants were offered a choice of being visited at home or attending a local clinic. All ten volunteers proceeded to interview; nine chose to be interviewed at home; one found it more convenient to be interviewed in the child's school and

offered to arrange this. Although several of the parents who volunteered had attended the recruitment meeting with a partner, there were no instances where both parents volunteered to be interviewed, so each interview related to a different child.

At the interview appointment, a duplicate Participant Information Sheet was provided, and informed consent to participate was obtained through signing copies of the Consent Form (see Appendix D). Interviews took between thirty and seventy minutes, and were audio-recorded using a Zoom H2 digital recorder to ensure completeness and accuracy of reporting and reduce the threat to validity of description (Robson, 2002, 2011). In some cases, brief written notes were made during the interview identifying points to be revisited before the end of the recording to enhance completeness and depth of data. As the interviews were viewed as contributing to data generation rather than data collection, active listening strategies were used throughout (Wengraf, 2001) and interviews were monitored for bias patterns as described above (Denscombe, 2003). An opportunity to ask questions was provided at the end of the interview both for ethical reasons, and as participants' questions might have provided additional information regarding parents' understandings. However in practice, few participants asked questions and those asked related to the progress of the research project. Following the interview, a Quotation Consent form (see Appendix D) was provided; this gave the participant choices regarding the use or otherwise of quotations from the interview in the completed report. Participants were also given an indication of how soon to expect a copy of the transcript for checking.

Immediately following the journey back to base, the researcher made brief notes regarding the context of the interview, as this can be significant when analysing data (Charmaz, 2006). The recorded interviews were transcribed using standard English orthography into Microsoft Word; this was used to aid retrieval of phrases or keywords when comparing data. All transcripts were anonymised during this process. The researcher transcribed all data to allow monitoring of interview technique (Charmaz, 2006) and of the data being obtained. Changes in interview style to a more research-based and less clinical perspective were made over the course of several interview cycles and minor changes in question wording were made because of this reflective practice.

Following transcription, a hard copy of the anonymised transcript was posted with a stamped addressed envelope and a covering letter (see Appendix D) to the participant. This enabled a limited form of member checking, in which the participant could check the transcript for accuracy and omissions, and return it for correcting within one month if they wished to do so. Lincoln and Guba (1985) described member checking as helpful for demonstrating credibility of findings. However, they were describing checks following analysis; in the present case checking occurred mainly for inaccurate or incomplete data, and as an opportunity for participants to clarify (Marshall & Goldbart, 2008) and confirm their meanings (Denscombe, 2007). It was also undertaken for the ethical reasons of informed consent and acknowledgement of data ownership discussed in section 3.4. Of ten participants, eight made no contact following receipt of the transcript, and two made contact to confirm their agreement. After

the one month deadline given in the covering letter or contact from the participants the transcript was accepted as complete, and coding and analysis of the data commenced.

3.5.3 Data coding and analysis

Several linked and overlapping operations are involved in using grounded theory methods of data analysis (Charmaz, 2006). Hence, description of the data analysis process necessarily makes artificial boundaries between operations.

In this study, the data from each interview was coded and analysed as it was generated in order to inform further data generation (Charmaz, 2006). Once the first three interviews were completed, the "constant comparative method" (Glaser & Strauss, 1967) was used throughout the analysis. In this grounded theory method, new and previous data were compared in an ongoing iterative cycle in order to cast further light upon the topic and refine or alter initial categories in the light of new information as appropriate (Charmaz, 2006; Strauss & Corbin, 1998). All coding and analysis was undertaken manually; qualitative data analysis software was not used, as there was a risk that "assumptions and limitations built into the software applications" (Coffey & Atkinson, 1996, p. 12) would influence but be undetected by a novice researcher.

The data was first expanded (Coffey & Atkinson, 1996) through line-by-line coding, to allow a wide range of possible themes to emerge (Charmaz, 2006). Line-by-line coding also acted as an "early corrective" (Charmaz, 2006, p. 51) to the researcher's biases and preoccupations as a clinician. Data were

coded using gerunds where possible to place the interviewees' perspectives in the centre of the emerging codes (Charmaz, 2006). For some transcripts, where participants had a simpler, more linear style of narrative, line-by-line coding became more akin to incident-by-incident coding at times. Line-by-line coding was followed by focused coding, in which the initial codes were compared to identify patterns and discrepancies (categories) in the ideas expressed by participants. At this stage, innovative methods of displaying and viewing data can be helpful (Miles & Huberman, 1994), and in the current study a form of diagramming (Charmaz, 2006) was used in which codes and categories were recorded and rearranged during iterative comparisons using MindGenius Education (Version 2) mind mapping software (MindGenius, 2006). The use of software for this task facilitated recording of alternative interpretations of the data, thereby allowing an ongoing "tolerance of ambiguity" (Maykut & Morehouse, 1994) which avoided early closure of useful categories. To reduce the threat to objectivity, demonstrate rigour, and enhance dependability, successive mind maps from this software were archived at several points during data coding and analysis to demonstrate how the final categories and theory were reached and to provide an audit trail (Robson, 2011). Axial coding (Strauss & Corbin, 1998), which can be used to specify the properties of categories (Charmaz, 2006), was not used, as this could have imposed a fixed framework on the data at an early stage, thereby closing down useful categories prematurely (Charmaz, 2006) and increasing the threat to validity of interpretation (Robson, 2011). Finally, each transcript was re-read for a narrative coding (Coffey & Atkinson, 1996). This identified key meanings from

each individual participants' "story", placing the data that had been "stripped" from the interviews during earlier coding back into context (Miles & Huberman, 1994) and identifying "unexamined agendas" (Charmaz, 2006). Both these functions were useful; for example, one child's unique diagnosis had influenced the parent's experience of the group attended, and another participant's prior experiences with local hospitals underpinned a focus on evaluating "the NHS" as a whole throughout the interview.

As the analysis proceeded, potential categories and themes prompted additional reviews of the relevant literature. Using this inductive approach, connections between theoretical categories from the coded data and models from the literature of parental adaptation, coping and empowerment were identified. A possible interpretation of parents' experiences of parent-based intervention groups was developed based on these perceived connections.

3.6 Project management

Project planning was undertaken prior to commencing the study. Planned timings were estimates, which altered due to external constraints (Maylor, 2003) as the project progressed. Significant constraints were the time required to complete the Integrated Research Application System form and obtain ethical approval letters, and lower than expected recruitment rates that necessitated an extension to the data generation phase.

The sequence of tasks as carried out during the project is presented in Appendix F. Supervision and support sessions were not included in this chart,

but took place as required, adding approximately twenty hours to the total time used.

3.7 Conclusion

In this chapter, the issues considered in selection of a research strategy, study design and methods to explore parents' understandings of the nature and purposes of parent-based information groups have been discussed. The conduct of the study has been described; the findings generated will be reported in Chapter 4.

Chapter 4

Findings

4.1 Introduction

In this chapter, the sample of ten parents who participated in this study will be described. Findings from the study will be presented in terms of four themes developed during data analysis. These themes were parents' experiences of intervention sessions, parental gains during session attendance, intervention facilitating a process of personal change and empowerment, and impacts of parent-based intervention courses in the wider context.

The themes will be illustrated using quotations from the interview transcripts, which have been anonymised. In this chapter, C denotes the child to whom intervention related, P the parent who attended the parent-based intervention course, and T the speech and language therapist involved in the intervention. Some study participants spoke about their child's other parent during interview; F refers to fathers and M to mothers mentioned in this way.

4.2 Description of the sample

One father and nine mothers of ten different children (nine boys and one girl) were interviewed for the study. The parent-based intervention groups discussed by these parents are shown in Table 1.

Table 1: Groups discussed during participant interviews

Participant	Groups discussed				
	Early Communication Skills	Early Bird	EarlyBird Plus	Makaton beginner	Makaton refresher
P1				X	X
P2	X				
P3			X		
P4			X	X	
P5	X				
P6	X				
P7	X				
P8		X			
P9	X				
P10	X	X*			

(*ongoing at time of interview)

Three of the parents in the study had attended more than one parent-based intervention group involving speech and language therapy. Two had attended Makaton training courses following either EarlyBird Plus or a previous Makaton course, and one had recently started an EarlyBird Programme course, which was still running at the time of the interview, following attendance at an Early Communication Skills group. Nine separate courses were discussed altogether, as some participants had attended the same groups. Parents 3 and 4 had attended the same EarlyBird Plus course, parents 5, 6 and 7 had attended one Early Communication Skills group, and parents 9 and 10 had attended another. The age range of the children discussed fell within the entry criteria for the group attended; parents entered Early Communication Skills groups when their children were aged between two years two months and two years seven months, EarlyBird and EarlyBird Plus between three and five years of age, and Makaton courses between three and four years of age.

At the time of the study, half of the parents interviewed had a child with a diagnosis of autistic spectrum disorder. Two other children were under investigation for autism or other learning difficulties. This reflected the observations of Law et al (2004), that communication difficulties can be either primary or secondary to other conditions, and that distinguishing between the two is not always possible in early childhood.

4.3 Parents' experiences of intervention sessions

4.3.1 Experience of the course as a whole

Parents perceived the parent-based intervention course as providing space to reflect on issues relating to their child with communication difficulties. Formal appointments, whether for groups or individuals, provided a structure that obliged parents to set aside time in their busy lives. This was something that could be difficult without an external framework, as this parent explained:

'...a huge advantage of going to group training is, is you – well, a formalised training session whether it's individual or group - is that you do allocate the time to it – em – but when it's sort of left to you – you know and you, you're trying to manage everything else on a day to day basis – it's quite difficult to sort of step back from it and think I'll just have a, a read [of the course handouts] and you know go back to square one.' (Parent 8)

The sessions also provided an environment with few distractions, allowing the parents to focus on their child and their child's difficulties and behaviour. The group sessions in particular provided an opportunity to focus without distraction, because the child was not present:

'It was an adult environment so – you didn't have to worry about the children or what they were doing or – because when it's – like

an individual session with the child there you're always watching to make sure they're alright...' (Parent 5)

For parents, another important feature of the intervention as a whole was its experiential character. Experience was perceived as superior to “being told”. For example, meeting other parents whose children had communication difficulties was more powerful for parents than hearing second-hand information could be:

'Everyone – says oh yeah there's other parents in the same boat - but you have to see it for yourself...' (Parent 2)

Reflection and active participation to develop skills and insights were encouraged. Parents perceived “hands-on” activities such as role-play and observation of video recordings as powerful tools for learning, as this description illustrated:

'...they would come to your house and do a video of you with your child and then we'd take, take those back to the [group] session – review them – talk about – you know what were the positives and what were the, maybe the areas – where – we could develop a little bit more which is very, it's very interesting when you watch those, you know, you think – oh, goodness me, you know, I'm like, saying “C, C, C, C” – you know instead of just – leaning back and – but er - but again its great, cause it just makes you think, right I – you know, I am sort of you know, going too – a bit too sort of fast and furious and stuff...' (Parent 4)

4.3.2 Opportunities provided by the group setting

When describing parent group sessions, study participants identified opportunities that the group setting provided and which they perceived as helpful. One of these was meeting other parents. Half the parents had wanted this before they attended the group:

‘...we just thought it would be a good thing to do to meet other parents...’ (Parent 3)

By sharing common concerns and experiences, parents found that they were not unique. The groups provided them with a rare opportunity to experience a setting where caring for a communication-disabled child was normal:

‘...everyone wants to talk about their own child don’t they and – you often don’t get – it, it was that, that sharing of experience and acknowledgement that – you know – em ... perhaps there aren’t many – sort of em, situations where you can actually talk about your own [communication-disabled] child and sort of say oh gosh yeah – you know – yeah oh yeah my child does that...’ (Parent 8)

Through hearing that others had similar experiences and emotions, and struggled with their situation, parents’ own experiences, emotions and struggles were validated. When both parents attended the group, hearing other parents’ stories also helped partners to perceive each other’s views as valid. This was illustrated by a father’s remarks about listening to his wife in the group:

‘...it’s different – when she voices it to you on your own you’ll think – we-ell – oh hang on a minute – but when you’ve got – a group there and they’re all voicing their opinions – it allows you to think well it’s not M it’s – it’s – happens a lot...’ (Parent 3)

As well as sharing similar experiences, group participants also shared different ideas. This broadened parents’ options, encouraging them to try new approaches with their child:

‘...at the time C wasn’t toilet trained but then I heard – one couple said that they’d toilet trained their child and I thought well – if they can do it I can do it, just cause he’s not talking, you know – so – good to get other people’s perspectives I think...’ (Parent 9)

Sharing different ideas and strategies led to joint problem-solving exercises as parents talked together and shared their successes and frustrations, as described in this quotation:

'...other parents have had the similar issues and they can – sort of say this is how we've dealt with it – and actually – you know – it could be that nobody's dealt with it very well and the – you know, there's a discussion about well how, knowing what we know now what, what could we do...' (Parent 4)

The views of other parents, as opposed to the views of professionals, were perceived as particularly valuable. Parents wanted to know how other parents coped:

'...it was good to mix with other people instead of just having – a professional there saying, "Yes do it all the time and in all these situations" – it's good to talk to other people, see how they – how they did it...if they used it [Makaton] at all...' (Parent 1)

Professionals also reinforced the perceived value of parent views through acknowledging parental experience and wisdom:

'...the speech therapist learns stuff off – us as well...' (Parent 5)

While parents shared information, the group setting also allowed them to make comparisons. They compared their own experiences, and reports of each other's children. Although somewhat embarrassed by it, parents reported making downward comparisons, which they found helpful as they discovered that their child's difficulties were less severe than they might have been:

'It probably sounds selfish – but hearing the other parents you kind of like put C on a scale – and then, because he's not at the bottom

of the scale you then feel, you know – better, which is a very selfish, but – kind of puts [it] in perspective...’ (Parent 9)

The impact of upward comparison was more variable. Some parents found knowing about another child’s progress encouraging:

‘...when [another parent] came to the third session she had news – that her little boy had just started talking – and it was a real inspiration...’ (Parent 5)

However, upward comparison could be problematic when a child had significantly greater difficulties than other children in the group. For example, one parent whose child was subsequently diagnosed with autism found comparison distressing during an early communication skills group, although other aspects of the group were still helpful. This ceased to be a problem when attending a more appropriate group:

‘...sometimes I felt as if C was the worst in the [early communication skills] group, because of his autism, and at that point it hadn’t been diagnosed...I felt as if, we were different – em – but then I still got quite a few good tips as well – but with the EarlyBirds [group] we’re all the same – and so I fit in better there...’ (Parent 10)

In the more appropriate group, this parent was able to balance upward and downward comparison and maintain a more positive outlook:

‘...we’ve got things that C does that other parents, you know, their children don’t do it and we’ve struggled with C and they’ve got problems that we don’t have – I mean you do sort of think, ooh god I’m glad that he doesn’t do that, you know and they’re probably thinking the same about some of the problems C’s got...’ (Parent 10)

Another positive feature of the group settings that parents identified was feeling safe. They saw individual sessions with a professional as potentially intimidating, whereas in the group parents felt less threatened:

‘...if all the sessions had’ve just been – with the speech therapist...it might of – well, I dunno, it might’ve been a bit sort of – not dictatorial but – bit like being at school...’ (Parent 2)

The feeling of equality and validation that arose from the similarity of their experiences, allowed parents to feel less vulnerable and to share more information:

‘...one to one you sort of hold back a bit I feel... I think because everybody was the same – I think we all opened, probably opened up more...’ (Parent 5)

At the same time, the presence of others in the group setting enabled parents to keep their emotions in check and approach discussion of their child’s difficulties with their partner more calmly:

‘...your emotions go into it whereas – you’re not going to in that environment because you’re there with these strangers – you know, and this official woman who knows what she’s talking about...so I think – I might – if me and F had been sat at home saying our – our different opinions on where C is at the moment I think I might have got annoyed with him or - or taken offence more whereas actually I thought – you know you sort of sit there and – with a lot more of an open mind...’ (Parent 2)

4.3.3 Challenges of the group setting

Parents identified challenges as well as opportunities associated with the group setting. Some perceived the time available for a group session as limited for the number of group participants. Parents sometimes felt rushed, with insufficient time to cover everything or raise issues that were important to them:

‘...we went there with a, you know, great big list of things in our mind of things we wanted to cover and – you know, other parents obviously want to cover things as well...as we were in the group session and the weeks went on – em, I suppose the disadvantage was that we couldn’t always – em – you know, ask the – specific questions that we wanted...’ (Parent 7)

Few participants attributed this time pressure to any cause. However, two participants thought that groups were offered because resources were limited:

‘...there’s always gonna be limited means within the NHS, you know – things have to be done in numbers...’ (Parent 6)

Parents also perceived tensions between the needs of individual group members and the group as a whole. They described how the group facilitators had a programme of information and activities to present during each group session. At the same time, individual group members had varying needs to express their experiences and emotions. This could be frustrating for other parents, even when they understood the need for support:

‘...well - you just didn’t always want to hear quite so much about another child... but, you know equally I can understand because you know I’ve been in, because C’s got other disabilities I’ve had other opportunities through the [Child Development Centre] group to speak to – other parents but – a lot of these parents – hadn’t necessarily had these opportunities...’ (Parent 8)

Parents in the groups differed in educational level and the children being discussed varied in terms of their diagnoses and progress. This meant that information provided to the parent groups needed to be kept relatively general, as this parent acknowledged:

‘...in a group situation you’ve gotta cover a wide area – em – a wide range of problems...’ (Parent 10)

However, this created difficulties for parents whose child was not sufficiently similar to others in the group. For example, one child had additional needs; the use of standardised procedures and published training materials exacerbated a lack of relevance for this parent:

‘...they work to a set programme... so whatever the child had to practice was something within the programme and, and some were more relevant than others and in a way – you know I know it’s difficult to fully individualise to – to each child’s level and needs but...I just sort of – thought – we acknowledge at the beginning that everyone’s different in terms of their – where they sit on the spectrum and yet – we, then they were all treated – the same...’ (Parent 8)

Participants recognised the challenge these issues created for group facilitators, identifying ways in which the tension between individual needs and group constraints was managed. For example, this parent described how group facilitators addressed the challenge of limited time by providing short but clearly identified periods for emotional support during group sessions:

‘...the first thing we do when we go in, is the teachers ask us, em – say a little bit about the sort of week you’ve had – and straight away that opens you up to talking about whether C’s had a good week a bad week, whether he’s done anything funny, anything naughty – and with everybody in the group saying a little bit...that makes you sort of connect a little bit more, just by having those first – it’s only about ten minutes...and we have a coffee break and it’s amazing how, you know, during that somebody’ll say oh what happened about such and such...and even though the coffee break’s only ten minutes, it’s just little chit-chat, that you get to know one another ...’ (Parent 10)

Parents also recognised that facilitators tailored their contributions to the needs of individual parents and children:

‘...all of the six children were very, at very different stages...T did identify, you know, you could see her professional skills coming out – and she did – very tactfully – erm, recognise that – they were all different – and did give different, the parents – I noticed certainly, whether they realised it or not but I noticed – that the different, different parents got different stuff from it – due to the level that their children were at – so whilst it was a group thing, you could see that she was – considering – she was doing, it wasn’t just a blanket thing for all of us...’ (Parent 6)

4.3.4 One-to-one sessions

Parents valued one-to-one sessions as they gave professionals an opportunity to “individualise” the input provided in the group setting, as this parent explained:

‘...the one to one – em – with the Hanen course was really helpful because they could just tune into C’s problems – and that’s what T did...’ (Parent 10)

This “individualising” helped to compensate for the tension between group and individual needs in the group sessions. “One-to-ones” also provided an opportunity for parents to raise issues they preferred not to discuss in a group setting, and additional time to ask questions:

‘...when T came to the house on a one to one basis we just fired them [questions] at her...’ (Parent 7)

4.4 Parental gains during session attendance

Parents described gains or benefits occurring during their attendance at intervention sessions. Parents gained skills they could use when interacting with their child, and they also experienced emotional benefits.

4.4.1 Skills-based gains

Most parents had expected or hoped for skills-based gains prior to attending the course, often because they felt frustrated by their inability to help their child:

‘...and I’d been crying out I think, I’d been sort of like, where, what - is there anything we can do you know, is there anything we can do to help – em – and so when this came along it was sort of like, yes – you know, I was really excited...’ (Parent 4)

Parents described gaining both knowledge and insight during sessions. They received information about stages of communication development, their child’s diagnosis and difficulties, and techniques and strategies for interacting or working with their child. They were asked to apply the information to individual children, including their own:

‘...she gave us handouts on... development of where children were at and – she tried to encourage us to then further down into that group, the third session I think it was – to, to try and identify where your child was...’ (Parent 6)

In this way, the parents internalised information as knowledge. This internalising was demonstrated during research interviews; parents described their children using the frameworks they had been given in the group, as in this example:

‘...he was saying at least fifty [words], because that put him on stage – on the third – group – you know – the third – development bit in – in her model...’ (Parent 2)

Parents developed an understanding of their child’s behaviour and communication needs, and the rationales behind different strategies:

‘...we realised that with C you, you’ve gotta intrude, because of his autism he doesn’t want you to – speak to him or play with him or anything like that...and he doesn’t really want to communicate back, so it was just little tips about learning how to – get in his way, and join in with him...’ (Parent 10)

Parents also gained insight during the sessions into their own behaviours. Through reflection, observation of themselves on video, and role-play activities with other parents, they became more aware of how they communicated and how this affected their child:

‘We had to do these little – scenarios where – [the therapist] gave us something that would interrupt a conversation – and each of us didn’t know what the other was doing... the other woman had to talk about where she lived, and I had to just keep interrupting her with other questions that were completely irrelevant – and it was just – I think it was – it was really good to sort of emphasise how – if C’s trying to communicate one way, but I’m not listening to him and trying to get him to do something else – how disorientating it would be to him... and I sort of went home and I went, oh my God, I do that to C without realising...’ (Parent 2)

As parents gained knowledge and insight, they were encouraged to integrate these. They became skilled in observing their child from their knowledge base, and acquired the ability to problem-solve, identifying issues relevant to their child, through group discussions and through encouragement and guidance from professionals. A significant feature of this process for parents was that they could apply the skills independently after the intervention was complete:

‘...they’d say, “Well, what’s happened this week?” you know – “what’s happened different?”...that’s what they’d do – they – they’d make you sit back and think about it yourself, rather than them just, them giving you the answer - ‘cause now we’re not – at the session – they would erm – you know – now we, now we’re not

there still – we, we're able to sit back and look ourselves at him – and understand what – what he's going through now...' (Parent 3)

4.4.2 Emotional benefits during sessions

Parents also reported emotional benefits from attending group sessions.

One benefit was reassurance, both through information provided by professionals and through comparison with other parents in a similar position. As well as reassurance that their child's difficulties were not as great as they might have been, parents were reassured that they were not to blame:

'[I thought]...maybe I haven't – played with C enough or spoke to C enough, 'cause he's very chilled – so...with the group it was reassuring that there's – others the same.' (Parent 5)

Another emotional benefit was reduced isolation. Several parents described isolation because their experiences did not match those of other parents they met on a day-to-day basis. Being in a group where their experiences were the norm allowed them to feel less alone, and gave them an experience of support from other parents:

'...I would say the biggest bonus or benefit for me of the course – was the fact that – there were other parents there, with children with special needs, and – you can, you were able to sort of talk about the problems that you had – and – for me that meant that I wasn't so isolated...' (Parent 4)

The group sessions also provided parents with numerous experiences of their ideas being respected and treated as valuable and useful. Joint problem solving, in which most contributors were parents rather than professionals, and the views of parents were seen as having greater authority, provided a powerful model of the value of parents' views. Professionals also reinforced this:

‘...I thought it was good – the feedback was there and they were able to give me straight questions [i.e. answers], but...they made myself – answer – my questions because they would say, “What d’you think?”...’ (Parent 3)

4.5 Intervention facilitating a process of personal change and empowerment

In their narratives, parents described a process of personal change occurring as the course progressed. Following the first group session, which they distinguished from subsequent sessions in their descriptions, parents described changes in their views, confidence and behaviour. Taken together, these changes resulted in an experience of empowerment, although this process posed some challenges.

4.5.1 Initial group sessions

The first group session was perceived by parents as qualitatively different from the rest of the course. It stood out as an entry point or gateway into the process that would occur during subsequent sessions. Some parents described the first meeting as providing activities that allowed them time to acclimatise to the group setting:

‘...personally, I’m quite nervous, going into, to a group session...but once - T did the introduction and explained – I think everybody – is the same really when they go to something like this...we all introduced – ourselves and introduced our children and showed some photos, if we had photos, and that, em – sort of... eased us – me into it and – I thought – thought the others – after speaking to the others after they – felt at ease...’ (Parent 5)

For other parents, the first session provided encouragement that enabled them to commit to the intervention process. Parents needing reassurance that

they had not caused their child's difficulties gained this during the first group session. At least one parent who had felt particularly concerned about this experienced a reduction in ego load that enabled them to look forward and focus on addressing their child's needs.

'...to have that reassurance from this group... it's made me then – move on and not dwell on that and think right – so this task in hand, let's deal with it – it's been able to make me – just get on with it really – instead of – feeling – my, em – guilt and blame has perhaps held me back a bit...' (Parent 6)

Parents who were sceptical about the group used the first session to weigh up potential benefits by attending despite their doubts. If they perceived that the group had something to offer them, their attitude changed and they engaged with the process:

'...I very nearly didn't go - but I thought, no, I'll go and do the course, and then I can say I've done it and – you know – and...after the first session with T I knew - it was the right thing to do because she really knew what she was talking about...' (Parent 2)

However for others, attending the first session of a group was a difficult moment. It involved acknowledging their child's difficulties and their need for help:

'...it's also a bit depressing – the first time you go...[because]... by going you're admitting that your child's got a problem – so – em – that was – so no it wasn't an easy – choice to make...' (Parent 10)

Overall, the first group session was seen as something of a watershed or transition point, as the parents in this study began a process of intervention leading to personal changes.

4.5.2 Changing view of parent, professional and child roles

A number of parents described changing their views about roles and responsibilities regarding their child's communication difficulties during the intervention process. They started attending believing that their child had a problem that needed 'fixing' by professional 'experts'. They did not see an active role for themselves, and questioned whether parent sessions were appropriate. However, during the intervention process they came to see their child as capable of developing communication in their home environment and their own role in facilitating this as key:

'...I thought – it's not about me, it's about my child... that was my first – feeling about it, but now I think – you do need, it is about parents – not equally but as, almost importantly...because – you're the one who's – developing your child now – you're the one that needs the awareness, you're the one that needs the education – you're the one that can make the difference – at home. You can't have – somebody – come and instantly fix your child for you.' (Parent 6)

Parents also took on a role as advocates for their child and educators of other adults, as in this example:

'...we, you know have shared information with, you know, his nursery and grandparents and other people that are close to him...we've shared different, you know tips on how to – talk to him and how to – communicate with him so I think – it's up to parents to – help their child along isn't it?' (Parent 7)

However, there was a delicate balance to be struck as this process occurred. Some parents entered intervention feeling guilty about their child's difficulties and worried that they were to blame in some way. Others felt that

offering parent-based intervention implied similar blame. One parent described how early group sessions had prompted feelings of guilt:

‘This was nothing that she’d said at all – but I started to feel, sitting in these sessions – you know, the parent only ones, that I thought – Oh God, I’m a terrible parent....It’s very hard not to take everything as a bit – of an insult – you know, you get oversensitive don’t you. Like – what do you mean I’ve been doing something wrong – then they never said we were but – you sort of sit there and think – oh ...’ (Parent 2)

Parents needed both reassurance and to understand that they had a role to play in addressing their child’s problems. As parent-based intervention proceeded, parents felt enabled to accept responsibility for facilitating their child’s development without feeling blamed. They came to see suggestions to change as being due to their child’s differences rather than to faults on their part. :

‘...it was – wasn’t – geared at me in that I’ve been doing it wrong, it was a – this is how everybody – this is a natural way of – teaching your children to speak – but because your children are different – we’ve gotta go along these lines, we’ve gotta go down a different route – and this is how...’ (Parent 6)

4.5.3 Increased confidence in ability to help the child

While not every parent described a change in attitude about their role, all of them reported increasing confidence in their ability to work with their child as the course progressed. Parents who entered the intervention process feeling frustrated and perceiving themselves as lacking skills to help their child developed a view of themselves as flexible problem-solvers, competent to address their child’s needs. They saw themselves as experts on their own

children, better placed at times than professionals to select appropriate strategies:

‘... [Before the groups] you feel pretty helpless, and you don’t know what to do...and you’re getting more frustrated... [Now] I feel as if I’ve got lots and lots of ideas and then you come up with ideas that even the speech and language therapists haven’t thought, thought of – because you get into that way of thinking and then you know your child so well so you know what would and wouldn’t work...’(Parent 10)

Parents felt confident both to help their child, and to deal with the reactions of others. They expressed acceptance of their child and more faith in their own parenting skills. They also felt less vulnerable to the potentially critical opinions of others, as demonstrated by this quote from the parent of a child with autism:

‘For me when I look back now ... it felt sometimes like I was letting C get away with things – you know, and it was like – and you almost, it was almost like you felt other parents sort of going – ‘tut’ ... and it’s those kind of things that I’ve relaxed about – em...and I’ve relaxed about because it’s like well actually C – is the way he is and it’s OK – and it’s almost like sod whatever anybody else thinks now...so that, that’s been yeah that’s been really good actually...’ (Parent 4)

4.5.4 Changes in behaviour

The changing beliefs of parents about their responsibility and ability to help their child were associated with changes in behaviour. Parents commonly described developing a more purposeful use of everyday situations, viewing them as opportunities for facilitating their child’s development:

*‘...every activity we do is an opportunity to communicate...’
(Parent 9)*

Parents described becoming more intentional in communicating with their child. They analysed their child's actions, decided what their child needed in order to progress, and managed their own responses accordingly. While some parents used new strategies such as Makaton signing, they more frequently adapted communication behaviours that they already used with their children. These adaptations included reducing unhelpful responses, increasing helpful behaviours, and introducing strategies that they knew were more appropriate:

'...I'm – so much more receptive to her, as soon as I hear – something now that's a new word – I'm, I'm in on it straight away – and I'm like, OK right – think – how, how am I gonna deal with this – and I don't...harangue her – into saying – what, say it say it, sort of thing – it's – I, I'll just repeat it back to her and I'll start using – the things that I've learnt, really' (Parent 6)

As well as facilitating communication development, parents also described applying the same skills-set to other situations. Some parents described improved interactions because they were able to work more effectively with their child. They could understand their child's perspective and apply the insights and strategies they had learned to situations that arose:

'...it just made me be – it made me be able – to – relate to him and – work with him through that situation...' (Parent 3)

Parents also used their skills to manage their communication-disabled child's behaviour more appropriately:

'... managing the behaviour...if something happens, understanding why that might be happening – could it be an environmental issue, could it be – em – yeah, just something around the child that is really upsetting them and it's – you know, trying to sort of, rather than shouting at the child and just going no

all the while, which actually...exacerbates the situation – it – it’s using different techniques, to do that...’ (Parent 4)

However, it cost parents some effort to implement the skills they had learned. Changing their responses to their child did not come naturally, and applying their knowledge and making purposeful choices as they interacted with their child required concentration:

‘...it’s quite difficult when you stop and think – what you’re gonna say first – ‘cause normally you just talk...’ (Parent 2)

It also took time:

‘...you need to be slow, it’s difficult when you’ve got everyday life you try and rush things through but just trying...’ (Parent 9)

Parents also had to maintain these changes in the vicissitudes of family life. This could be difficult as other priorities arose. For example, this parent struggled to maintain strategies when her child was admitted to hospital:

‘You’re really good when you’re doing it and you’re doing all the, the right things and then... I guess we were so worried about him, and – we ended up sort of pandering to – his needs a bit more – and then, I think...you know, you just suddenly the things [behaviours] that perhaps – we each tried to get rid of have slowly crept back in...’ (Parent 8)

4.6 Impacts of parent-based intervention courses in the wider context

As well as describing parent-based intervention sessions, and the process of personal change they experienced, parents discussed the ways in which intervention had impacts on their wider environment.

4.6.1 Perception of impact on the child

Study participants perceived positive changes in their children's communication following parent-based intervention. They described increased motivation and effort to communicate, and additional communication skills, as in this example, where the parent had attended a Makaton signing course:

'...whereas before he would have been like, "Ur, uh ur", and point at things – now – he – he will try and do sign...he'll sign, or he'll make some kind of noise, and if people go, "What?" he'll try and sign more, whereas before he would have just given up he's, like, "No, this is what I'm doing, take note"...' (Parent 1)

While some participants unambiguously attributed the changes in their children to the skills they had learned during intervention, most viewed them as due to a mixture of factors. In particular, the child's readiness for change was seen as important, possibly reflecting the shift in parents' views from expecting their child to need "fixing" to perceiving their role as facilitating the child's development:

'...it's er – a combination I think – you know, he's just – reached a stage in his life where he's just – going – em – it's – I think certainly speech therapy helped, the groups and I think, you know, us – talking to him in a certain way and – just taking on the, the different – hints and tips that they gave, you know and just – how to communicate, that's helped...' (Parent 7)

4.6.2 Impact on parent's relationship with child

Many parents in this study identified positive changes in their relationship with their child following parent-based intervention groups. Understanding their child's perspective and having strategies to cope with their child allowed parents to remain calmer and more relaxed in difficult situations:

‘...the situation doesn’t get – heated as much as it used to – I’m not saying there’s no moments but there’s very – few compared to you know what it used to be...’ (Parent 4)

Increased insight into their child’s difficulties also enabled parents to view their child in a more positive light. They reported seeing their children as children first and focusing less on disability. They felt more aware of their children’s strengths and reported seeing them as more competent than before the course:

‘...I think I – I saw him as a much older – little boy after [the course]...’ (Parent 2)

Understanding their child’s behaviour and needs, and feeling more confident to address these, allowed parents to enjoy their children more than previously:

‘...it’s brilliant to have that sort of relationship with him now ...’ (Parent 3)

4.6.3 Impact of attending the course with other carers

The relevance of parent-based intervention to other adults in the child’s environment was emphasised by most of the parents. The two participants who accessed EarlyBird Plus courses valued the fact that the child’s teacher or teaching assistant also attended. They saw this as beneficial because they could share information and work together more closely to help the child:

‘...his helper was there from school see, so...I thought that was good as well, because – we built a relationship – with his helper...’ (Parent 3)

Parents welcomed the opportunity to attend groups as a couple; six out of ten participants in this study attended at least part of a course with their child's other parent. Several parents expressed concern that groups ran during the day, which they saw as preventing some fathers from attending. The one father in the study felt that he had benefited greatly from the course, and wanted other fathers to have the same opportunity:

'...one of my suggestions would've been maybe the group should be of an evening...or more accessible to couples...because obviously – there was – there was only sort of – erm – mothers there – or – you know whoever could be there...but because of my hours I worked and my rota – my shift work – that was the only reason why I could really go –em – which is – you know obviously I landed on me feet there and I – through going – obviously I got that much out of it and I thought it was that good – I thought – you know, other people should be able to – you know, like a working class husband – should – be able to access that sort of – sort of group' (Parent 3)

By attending together, both parents were able to contribute to the process. In the sessions, parents filled in information that the other forgot to mention, added their own perspective, and found out about each other's views:

'...a lot of things that came out of my mouth didn't come out of F's mouth – and a lot of F's opinions I was like, oh! – I didn't realise you thought that...and so it was really interesting...' (Parent 2)

Interviewees reported that for both partners, it was easier to learn first-hand. Partners who attended the group could benefit from experiencing activities rather than being told about them, which enhanced their learning. If one parent attended alone and tried to relay information to their partner, it was impossible to pass on everything. However, when both parents attended the

sessions, both had access to all the information and got a fuller picture of what was presented:

'I can only tell him so much, you know – I can only come back from like the Hanen course and say, oh we should have been, should be doing this, or I showed him the paperwork we were given – but it's very different to actually being in the room and being taught it and, perhaps watching video clips on it like they do as well and – and em – that, that makes a huge difference I think...' (Parent 10)

Parents were also able to retain more information, and help each other to make more sense of what they had heard, as they discussed ideas after the session was over and applied them in the home situation:

'...if I didn't – get the grasp of something - erm – later on – em – we em – something that happened - we would both sit and watch [C] and we would – ah – that's what happened – that's what the group were on about – you know, it was a lot better – in – in that respect...' (Parent 3)

Through both attending the sessions, parents felt their child could receive more help as each parent spent time working on target strategies in different situations:

'...we've both got our different ways of – playing with C... like F used to take him down to the play area and – you know – he, he'd do his – communication with him, you know – down the pole and going again, you know – C's turn now and – he'd do it that way whereas I'd perhaps – be here playing with him – on the floor and do it, you know...' (Parent 7)

For some parents, attending together was also perceived as sharing responsibility for their child and as strengthening the family unit:

'...it's – brought us closer together as a little family – you know, because – I think because F come along... the fact that we went together – was brilliant – because we shared the experience, which obviously working opposite hours is something we don't

always do -, we went together, united front, we're going to help our son ...' (Parent 2)

Study participants perceived the benefits of other carers attending sessions as sufficient to warrant offering places on the courses for members of their extended family, particularly grandparents. For some this was because a grandparent had a significant caring role with the child:

'...that was what I'm, I'm disappointed with, is that – it was never suggested to me that mom could come because she's like a parent, she's as equally as a parent to – C as I am – really, the amount of – input she has with her – em – cause there were couples there – and my mum is like – C's – other parent...'
(Parent 6)

Others saw the groups as a means to encourage their family to support them more. This parent hoped to facilitate the use of consistent approaches with their child, and also to increase understanding of both child's and parent's needs:

'...I think it would have em, perhaps helped C in terms of every one taking a – particular approach [and] I also think – you know from a – touching on sort of some of the things, like how hard it is for parents in terms of dealing with other people's – em, behaviour towards you – I think it might have – helped with that – because it's not just people that don't know you, it's people that do know you that – have opinions and things that – are often – unhelpful...'
(Parent 8)

4.6.4 Costs and benefits

Parents perceived both benefits and costs to attending parent-based intervention groups. Some costs were associated with getting to the sessions, and were organisational. Travel, childcare, and leave from work all had to be arranged:

‘...it was like – one morning a week for four weeks – it was a nightmare with work...’ (Parent 1)

There were also emotional costs. For some parents, attending the group was a painful acknowledgment of the extent of their child’s difficulties. For others, increased insight into the impact of their behaviour on their child could lead to feelings of guilt. Although the end results of these processes included increased skills and confidence to help their child, painful emotions were part of the experience as well.

Parents discussed their attendance at the courses in terms of weighing up perceived costs and benefits. For the benefits to outweigh the costs, parents needed to feel that their child had gained in some way, either directly or through their wider environment, and that this gain was more than temporary:

‘What we all want is for our child, children to – to actually benefit in some way in that they’re – you know – more open to actually able to function in, in the world or, or – or that they’re happier or that, you know just as a family you’re able to function... has it actually led to real changes in behaviour...that have been sustained, you know ...’ (Parent 8)

They considered in their interviews how benefits might be maximised or enhanced to improve the balance with costs. Some viewed this balance as partially under their control. They described committing to the group and to the activities as important for themselves:

‘...because I – got quite involved in it – I got a lot more out of it...’ (Parent 6)

They saw commitment as a responsibility not just to themselves, but also to other parents attending:

‘...it annoyed me that the other parents didn’t turn up... It’s letting down – letting other families down – if you can’t be bothered to go fine but – don’t commit... if you can’t commit, then wait for the next [course]...’ (Parent 2)

At the same time, they believed the benefits of attending also depended on the match between their child’s needs and the group the parents attended. If the needs of the child, and hence of the parent, were not addressed in the sessions, the costs of attending outweighed the benefits:

‘...I think I’d say go [to the group] – but – at a point when the child’s got limited communication rather than no communication – cause otherwise you’re just sitting there thinking well – my child’s not talking at all how can I – how can I relay this how can I adopt this...yeah, you get even more frustrated because like – oh, my child’s not even doing that, how can I develop on that?’ (Parent 9)

Finally, while some parents in this sample expressed confidence about carrying on independently, other parents saw a level of ongoing support as a helpful way to ensure the benefits of the intervention were sustained. This was necessary, in their view, because children’s needs changed as they developed. Issues irrelevant at the time of the group became pressing, or children made progress so that parents needed to move on a stage:

‘...we’re having, sort of great difficulties with – with the eating, and, you know things like, things that we went over in the course but perhaps, because they weren’t necessarily that relevant for you at the time or because you had a handle on them at the time – you know, you – you then – sort of – that, I guess they just change don’t they and, and you almost need constant kind of [support]’ (Parent 8)

4.7 Conclusion

In this chapter, the findings from ten participant interviews have been presented. In Chapter 5, these findings will be considered in terms of the research question, and a theory developed from the findings will be presented and explored. Some implications of the findings and theory will also be discussed.

Chapter 5

Discussion and Conclusions

5.1 Introduction

The aim of this study was to explore parents' and carers' experiences of attending parent-based intervention groups, by answering the research question of how they understood the nature and purposes of these groups and developing a preliminary theoretical understanding of their experience grounded in the study data and relevant literature. All participants in the study were parents, and therefore the discussion that follows will refer only to parents.

In this chapter, the research question is revisited in the light of the study findings. Connections between parents' experiences of parent-based intervention groups and processes of adaptation, coping, and empowerment are discussed, and a preliminary theoretical model of parents' experience of parent-based intervention groups is presented. The findings are cross-referenced to existing relevant research. Some implications of the study findings for clinical practice, the current knowledge base, and further research are discussed, alongside limitations of the study.

5.2 Parents' understandings of the nature and purposes of parent-based intervention groups

Parents perceived the parent-based intervention groups they attended as a specialised environment, usually provided as part of a broader intervention, which they entered for specific purposes. Two of these purposes, providing

parents with skills to help their child and providing opportunities for them to meet other parents facing similar challenges, were processes that benefited parents and/or their child, and corresponded to the stated purposes of the interventions (Girolametto et al., 1986; Leverton & Peden, 2008; National Autistic Society, 2007) and to parents' expectations. The third purpose, maximising limited resources, had no direct benefit for children or families but instead related to the perceived needs of the intervention provider.

All the study participants saw the primary purpose of intervention as providing parents with a set of skills to facilitate their child's communication development. Some parents also reported gaining skills for interacting with their child more effectively and for managing their child's behaviour. They described increasing confidence in their parenting skills and reported being able to intentionally adapt existing behaviours, matching their responses more appropriately to their child's needs. A key feature of these skills for parents was being able to help their child independently of professional direction, and to continue helping them after the intervention ended.

Study participants' perceptions of developing skills and confidence through parent-based intervention groups corresponded with some observations in the literature. Parents in the study of Hanen groups by Baxendale et al. (2001) identified development of intentionality and "fine-tuning" of existing skills as outcomes of those interventions. Increased parental confidence during intervention was observed by Gibbard (1998) reporting on groups (Gibbard, 1998), and reported by some parents in the study of individual interventions by Goodhue et al. (2010). Continuing confidence to use learned

techniques after group-based interventions ended was reported by Gaines and Gaboury (2004). These three studies investigated approaches that used directive models of parent-based intervention; the current findings show that parents can gain similar confidence in groups using an interactive model.

However, the current study does not fully support the assertion by Kaiser (1993) that parents are “tuned in” to their child’s needs and communication attempts. Whereas parents showed evidence of insight into older children in the study of school leavers’ communication by Lindsay and Dockrell (2008), parents’ descriptions in the present study of increasing insights into their younger children as a result of intervention suggest that parental insight should not be assumed, and that there is a place for supporting the development of this skill.

The second purpose of parent-based intervention groups identified by participants was the opportunity to interact with other parents whose children also had communication difficulties. Study participants perceived several benefits from this. Through comparison and sharing, they confirmed that their experience and their child’s difficulties were not unique. Some found this reduced the sense of isolation they felt, thus supporting a similar description of reducing parental isolation given by Behr (1997). They gained an experience of their situation as normal and perceived meeting parents with similar emotions and concerns as validating their own experiences, findings which supported the descriptions of Hornby (2000) and observation by Hodges and Dibb (2010). Opportunities for comparison also provided reassurance, as parents discovered that others were worse off in some way.

Two parents perceived a third purpose of offering groups as maximising limited resources through providing intervention to several families at once. It was not clear whether these participants saw this as a primary or secondary purpose of the groups they attended; both mentioned the matter briefly, and spent more time discussing the other two purposes identified. However, this finding suggests that parents are aware of the potential for viewing groups as a cost-saving measure exemplified by Cunningham and Davis (1985), and it is possible that more participants would have raised this issue if asked directly.

Parents' descriptions of the group environment indicated several distinctive characteristics. They perceived groups as providing a safe space for parents to reflect on their child, and as combining elements found in group learning environments and support groups. There was an emphasis on learning through experience. Parents saw group sessions as part of a process that stimulated personal change and empowerment, and which could be costly.

Parents perceived the first meeting of a parent-based intervention group as somewhat different in character from subsequent sessions. It was seen as significant for committing to the process and allowing time to acclimatise. For some parents, there were particular issues to be addressed during the first session, such as acknowledging that a child needed help or addressing the fear that they had caused their child's difficulties. This perception of initial group sessions as an entry point to a process has been acknowledged in the literature; Nichols and Jenkinson, for example, described the first session of a support group as important for establishing the "framework" within which the group will operate (Nichols & Jenkinson, 2006, p. 88).

Study participants' perceptions of the group as a safe space partly arose from being with other parents, which they found less intimidating than facing professional attention alone. This supports Bray's suggestions that professionals can be perceived as threatening and that this perception is reduced for group members (Bray, 2002). Parents also felt able to disclose issues to other parents which they would not have disclosed to a professional, echoing findings from Beresford's parent interviews (Beresford, 1994). Sharing also engendered a sense of safety; as study participants shared common challenges and experiences, their views and their partners' views could be seen as normal, acceptable, and valid. This finding confirmed descriptions in the literature of both support groups and parent education groups; Nichols and Jenkinson (2006) described support groups as providing validation of members' views through the acceptance and shared experience of other group members, and Hornby (2000) described sharing and validation as enabling parents to see education groups as safe places.

Within this safe setting, parents were able to take advantage of opportunities for learning from and with other parents in the group. Didactic activities were few; most learning occurred through experiential activities made possible by the group setting. One example of this was role-play, which study participants perceived as a powerful method for developing insights into their own communication styles and their children's needs. This reinforces a similar finding by Baxendale et al. (2001), whose group participants reported that role play helped them to empathise with their child. Another finding corresponding to those of Baxendale et al. was the confirmation of parents' self-reports of their

learning through their use of conceptual frameworks provided during intervention to discuss their children during interviews.

During groups parents discussed different views as well as similar experiences, echoing Hornby's description of parent education groups as exposing parents to a range of ideas (Hornby, 2000). They engaged in problem solving together. Parents in the current study reported effects from this supporting those described in the literature. They encountered new ideas for managing their situation as they discussed problems together, offered suggestions to each other, and increased the flexibility of their responses (Gibbard, 1998). They were also inspired to tackle challenges they had been avoiding (Whitaker, 2001).

Groups also provided opportunities for comparison. Descriptions in the current study about the use of comparison by parents, their embarrassment about this, presence of positive and negative results of social comparison, and parents' method of balancing this by selective comparison, all correspond to findings by Hodges and Dibb (2010) in their study of parent support groups. Parents' descriptions in the present study of viewing success in another child as encouraging also support Whitaker's argument that change in other group members engenders hope for oneself (Whitaker, 2001).

The groups parents described had a dual nature that reflected the features of both education and group support identified by Cunningham and Davis (1985). The acquisition of knowledge, skills, insight and understanding described by study participants matched the definition of parent education groups given by the United States' National Parenting Education Network

(National Parenting Education Network, 2011). At the same time, processes characteristic of support groups occurred, such as providing interactions that reduced isolation and enabled comparison (Nichols & Jenkinson, 2006) and validating group members' experiences through hearing narratives similar to their own (Wright et al., 2008). This duality was also demonstrated in parents' perceptions of tension between two purposes of the groups.

Study participants perceived the groups as contributing to a process of personal change and empowerment. They saw empowerment as due partly to developing practical skills and insights that enabled them to help their child, thereby taking control of a situation where they had previously felt helpless; this supported the suggestion of Porter and McKenzie (2000) that an increased sense of control can be empowering. However, they also viewed emotional factors as significant. For example, reassurance that they had not caused their child's communication difficulties was seen as important because it reduced feelings of guilt, allowing them to move forward and address their child's needs; their descriptions matched the "reduction of ego load" identified by Aveline and Slavson (Aveline, 2003; Slavson, 1958). It was also significant because reassurance that they were not to blame for their child's difficulties enabled parents to accept responsibility for helping their child without feeling undermined, a risk that was identified by Porter and McKenzie (2000). Another important feature of empowerment was the experience for parents that their views could be trusted, and that at times they knew more than professionals did. Overall, the process described by parents in this study corresponded to Behr's description of parents learning from each other, providing a model, and

an experience, where parents, rather than professionals, could identify the best options for individual children (Behr, 1997).

Parents reported moving from a view of their child's difficulties as needing to be "fixed" to seeing them more positively as able to learn from their environment. They also came to see themselves as having a role in facilitating this, and being competent to do so and to advocate for their child. This initial perception of being unable to help their child prior to intervention corresponds to several reports in the literature. Baxendale et al. (2001) found that parents attending a Hanen course began by expecting direct therapy for their children and changed their views as the course progressed. Some of Hayhow's interviewees also described themselves as unsure that they could carry out intervention tasks initially (Hayhow, 2009), and Glogowska (2002) noted that parents expected to carry on exercises between appointments, but tended to see the SLT as the "expert" who knew which exercises were required.

Increased faith in their child's abilities corresponded to a similar finding by McDade and McCartan (1998), who reported that parents focused more on their children's strengths following Hanen groups. Parents' views of their children as capable of developing may have been reflected in their view of the cause of changes in their child. While acknowledging their new skills, parents in the present study attributed their children's progress to a mixture of factors. This corresponded to the views of parents in the study by Boyle et al. (2007), who did not necessarily attribute their children's progress to the interventions they received. In the present study, parents saw their child's progress as depending upon their stage of, and readiness for, development, suggesting that part of the

shift in their perspective was towards children having their own role to play in their development.

Parents reported that as empowerment and confidence to help their child increased, they accepted their child's difficulties and the parent-child relationship improved, suggesting that the concerns of Lees and Urwin (1997) and Cunningham and Davis (1985), that parent-based interventions can disrupt the parent-child relationship, were not fulfilled in these groups. Instead, Kaiser's suggestion that the bonds between parents and children can be enhanced by parent-based interventions (Kaiser, 1993) was supported. Parents also demonstrated their acceptance by their reduced concern about the views of others.

For study participants, attending groups held costs, which fell into three types. There were practical costs of childcare, travel, time, and leave from work, corroborating potential costs suggested by Pennington et al. (2009). Emotional costs, associated with accepting their child's difficulties and with personal change, were also identified. Parents also described costs in terms of effort required to implement and maintain the skills they had learned; these findings mirror those of Goodhue et al. (2010) for speech and language therapy, and findings identified by Watts Pappas and McLeod (2009) in their review of parent-based interventions across a wider field of allied health professions.

Parents described weighing costs against benefits, a finding that supports Glogowska et al.'s report (Glogowska et al., 2002). Participants identified necessary conditions for the groups to be beneficial, such as appropriate matching of needs in the group, parental commitment, and

maintaining progress. They saw the role of the professional facilitator in balancing tensions between different needs as important. They also described ways in which benefits were, or could be, enhanced. These included the provision of one-to-one sessions, and attending the group with other carers.

5.3 Processes of adaptation, coping, and empowerment: the role of parent-based intervention groups

The parents interviewed in this study had discovered that their child was not developing communication normally, and had experienced concern and frustration as a result. All had reached a type of crisis point, where they were prepared to set aside time and incur practical costs in order to address their child's communication difficulties through a parent-based intervention course. However, after completing the course parents did not always attribute any changes in their child to the intervention they had received. What they consistently identified as resulting from attendance were changes in their own behaviour, feelings, and attitudes.

Some of these changes were common to parents regardless of the severity and aetiology of their child's communication. All described themselves as having adapted their behaviour to their child following the groups, purposefully using strategies to facilitate communication. They described themselves as doing this autonomously, making their own decisions about which strategies to use with confidence. Several reported acting as advocates for their child, attempting to educate other adults about their child's needs. Parents described themselves as more confident in their own skills. Many also

described developing acceptance and a more positive attitude towards their child.

These behaviours and attitudes reflected definitions of successful adaptation (Anderegg et al., 1992; Clawson, 1996), appropriate coping strategies (Beresford, 1994; Canam, 1993), and empowerment (Gibson, 1995) in parents of children with a variety of chronic conditions. Hence, it appeared that for parents in the current study, their experience of parent-based intervention as a whole was associated with developing aspects of adaptation, coping and empowerment regarding their child with communication difficulties. This is supported when the components of these processes described in the literature are compared with the study findings. For example, seeking and obtaining information about their child's difficulties, which was reported by parents in the current study, was identified in the literature as an adaptive task (Canam, 1993), necessary for the first stage of empowerment (Gibson, 1995). Obtaining information is also required when obtaining knowledge (Clawson, 1996), exploring the situation as part of confronting it (Anderegg et al., 1992) and for problem-solving (Beresford, 1994).

To some extent, parents' experience of adaptation and empowerment was unsurprising, since the stated purpose of intervention was to provide parents with skills to help their child through a flexible interactive approach to facilitating communication development. However, adaptation and empowerment were implicit, rather than explicit, purposes of intervention that coincided with planned outcomes rather than being managed. Better understanding of how adaptation and empowerment occurred for these parents

could provide information for clinicians wishing to facilitate parental adaptation or empowerment in other settings, an understanding of the role of group sessions in the process, and information about how parent-based intervention groups function in general.

Most of the parents in this study attended courses that included both individual and group-based sessions. Both contributed to the experience of adaptation and empowerment that parents described. However, groups appeared to play a specific role. They provided a setting in which parents' experiences could be normalised, where their skills and emotions were validated, and where they felt safe to explore issues in more detail with their peers than they would have in one-to-one interventions. In effect, the group was a safe space for "discovering reality" and "critical reflection" (Gibson, 1995), and for exploring and acknowledging their situation as part of confronting it (Anderegg et al., 1992). It was also a safe place to vent their emotions, a coping strategy identified by Beresford (1994). Groups also afforded opportunities for comparison with others; viewed as a coping strategy in its own right (Beresford, 1994), comparison has also been regarded as enabling parents to identify their own strengths and so increase confidence in their own abilities during the process of "critical reflection" (Gibson, 1995). It has also been considered helpful for the adaptive task of accepting a child's condition (Canam, 1993). In the present study, parents also reported upward comparison enabling confrontation (Anderegg et al., 1992).

While parents experienced these processes with other parents, the professionals who were present also contributed to the opportunities available.

They provided information, and guided activities that facilitated learning, thereby helping parents to develop useful insights, skills, and coping strategies. Some experiences and information could be delivered by professionals equally well in one-to-one situations, but others, such as role-play and group problem-solving, were made possible by the group. Insights into their child and their child's difficulties, gained experientially through role play and discussion with other parents, enabled parents to understand both their child and their child's perspective (Beresford, 1994; Canam, 1993), and to alter their expectations and make realistic plans (Anderegg et al., 1992). Experiencing problem solving in a group provided access to a wide range of experience and ideas, possibly enhancing the development of this important coping strategy (Beresford, 1994; Canam, 1993). The respect accorded to parents' views by other parents, and by professionals, enabled parents to see themselves as capable of "taking charge" to help their child independently (Gibson, 1995).

Thus for parents in the current study, their experience of parent-based intervention groups appeared to contribute specific and unique features to a process of personal change. Based on this, a theoretical model has been developed to explore how parents may experience these groups.

5.4 A theoretical model of parents' experience of parent-based intervention groups

The parent-based intervention groups explored in this study involved two forms of interaction for parents, each of which could have been provided

elsewhere. However, in the group setting both interactions were combined, producing a different parental experience (see Figure 1, page 99).

Figure 1a illustrates interaction between the parent and a professional. Such interactions may occur in one-to-one settings, and include activities such as seeking or receiving information. Interactions have an impact on the parent, which is indicated by the overlapping, vertically hatched area on the diagram.

Figure 1b illustrates interaction between the parent and a parent group. Here, activities such as sharing or comparison are possible; the impact is again shown by the overlapping area, which is horizontally hatched.

In parent-based intervention groups, both types of interaction combine in one setting, as shown in Figure 1c. This has several potential effects on the individual parent. The overall area for impact increases, as illustrated by the increased area of overlap and hatching in the diagram. Impacts from both professional and group are available simultaneously, as shown by the vertically and horizontally hatched areas. A new form of interaction, between parent, professional and parent group, is introduced and leads to the possibility of a combined impact on the parent, shown by cross-hatching on the diagram. Finally, the intensity of the parent's interaction with the professional may be reduced; the professional is focussed on the group as well as on the individual, as shown by the un-shaded area of overlap, and some of the impact of the professional on the parent is experienced jointly with other parents in the group, as illustrated by the crosshatched area. This aspect of the model is supported by the study finding that parents perceived the groups as less threatening than individual interventions might have been.

Figure 1: Combining interactions in parent-based intervention groups

Figure 1a: Parent-professional interaction

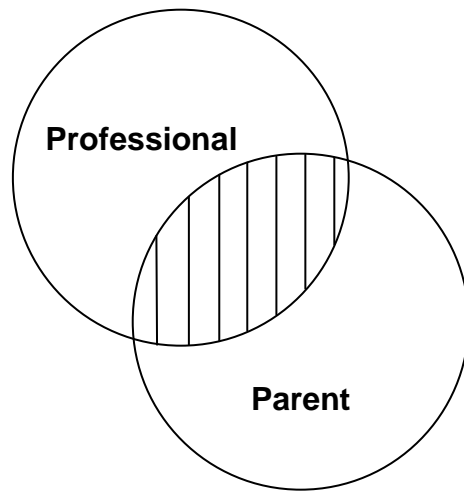


Figure 1b: Parent-parent group interaction

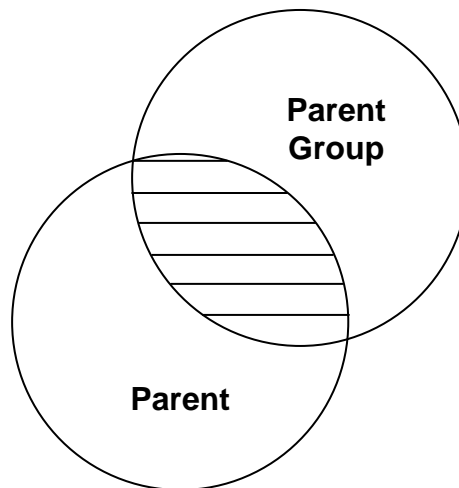
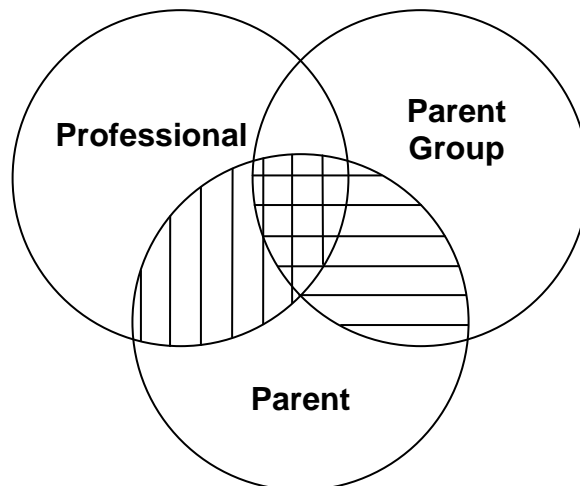


Figure 1c: Parent-professional-parent group interaction



Findings from the present study also support the existence of the simultaneous and combined impacts identified above. For example, Figure 2 (see page 101) illustrates the situation where impacts from both the professional (Impact A) and the parent group (Impact B) are available simultaneously. In effect, these two impacts can be added together in the parent-based intervention group setting. Most study participants reported examples of this cumulative effect, such as feeling reassured about the level of their child's difficulties both by information from the professional (Impact A) and through comparison with others in the group (Impact B).

Figure 3 (see page 101) illustrates one example of combined impact, in which the parent, parent group and professional all contribute to create an impact not otherwise available. The example shown in this diagram is that of role-play activities within the group leading to increased parental insight regarding communication with their child. Professional, parent and parent group each contribute to the eventual impact through different means. Interestingly, this example also illustrates the importance of commitment to attend and engagement with the process that parents identified as necessary for the group to be as effective as it could be.

Figure 2: Cumulative effect in parent-based intervention groups

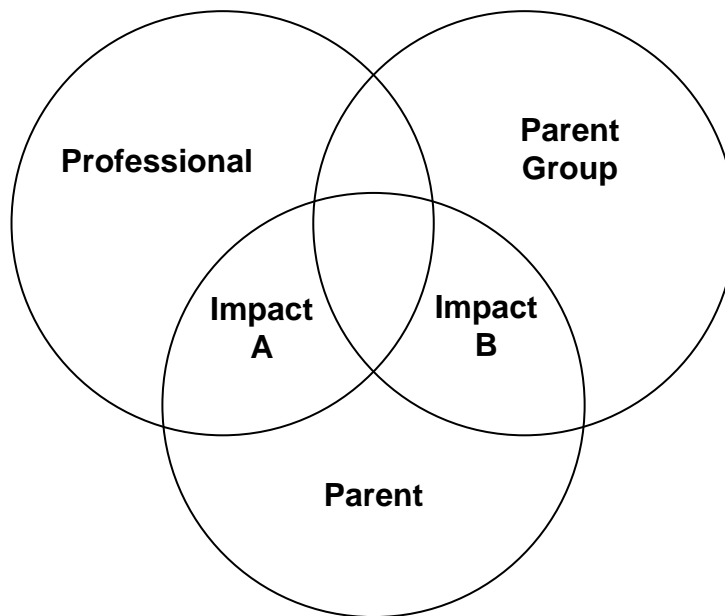
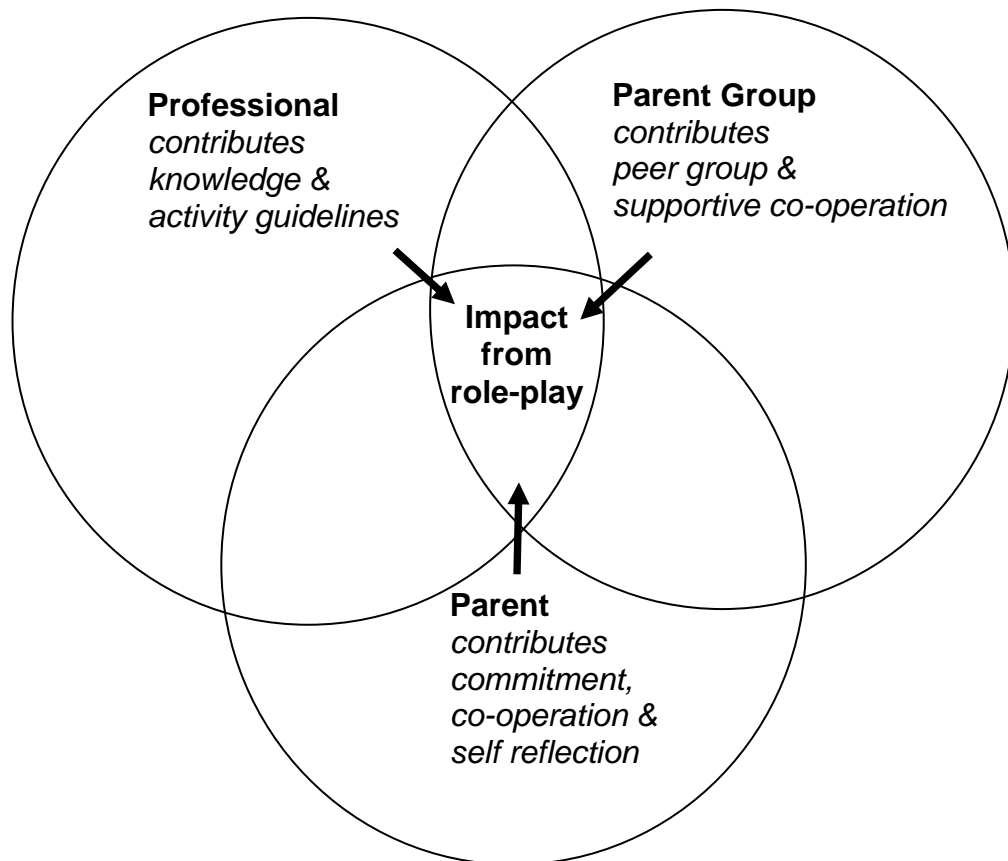


Figure 3: Example of combined impact in parent-based intervention groups



The model can also be used to illustrate other findings from the study. For example, the issue of “fit” between the parent and the group they attended was raised by several participants. They saw being well matched with the rest of the group as necessary for the intervention to be beneficial; if the match was poor, parents became frustrated or distressed. Figure 4 (see page 103) illustrates the contrast between “fitting” and not “fitting” into a group. Figure 4a shows the situation of a parent whose needs are well matched with those of other parents in the group. The hatched area of overlap between parent and group denotes the extent of common ground between them and hence the potential for experiences such as validation and normalisation. Figure 4b shows the situation of a parent whose needs are less well matched with the rest of the group. The reduced size of the hatched area illustrates how there is less common ground between parent and group in this case, and hence less potential for these forms of support.

Figure 4: Comparison of “fitting” or not “fitting” the group

Figure 4a: Parent well matched with other parents

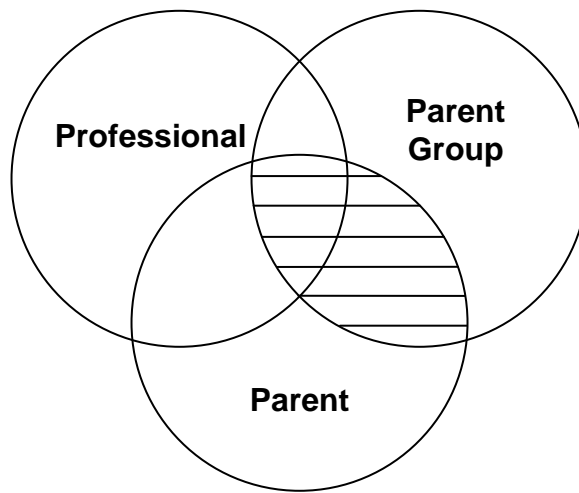
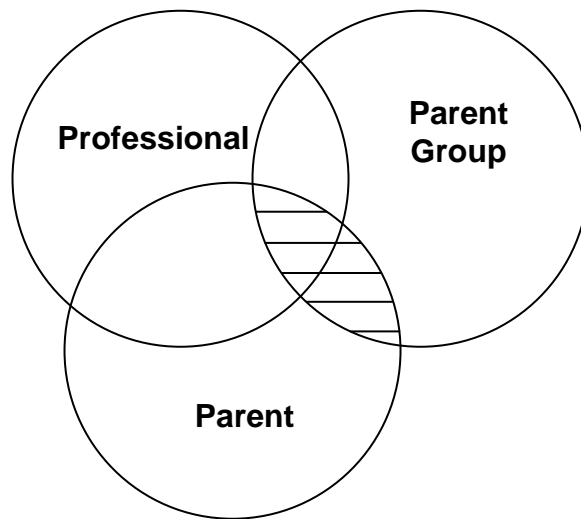


Figure 4b: Parent less well matched with parents



5.5 Implications of the study

This study was undertaken to explore parents' understandings of parent-based intervention groups within a particular local context. As this was a topic area not previously studied as a whole, it was anticipated that the findings could provide a preliminary overview of the subject and indicate areas for further research. The project was necessarily limited in scope and size; exploration of the same research question with an extended sample population, enabling data saturation and theoretical sampling, could be useful for indicating whether the experiences reported are consistent across a wider sample. Nevertheless, the study raised interesting issues that could have implications for further research and for clinical practice.

Through its exploratory nature, the study addressed some previous bias in research towards negative issues, as it allowed parents to identify positive outcomes as well as costs that they perceived as significant in their own contexts. These details could be used to inform investigations such as surveys into costs, outcomes and satisfaction evaluations, making them relevant to service recipients rather than constrained by clinician or researcher agendas. Parents also identified several mechanisms and processes that provide possible avenues for further exploration. Certain areas, such as how parents weigh the balance of costs and benefits, or factors associated with maintenance of outcomes, might be explored in greater depth. Others, such as how parents' views of their competence and role change during intervention, could be studied from a longitudinal perspective.

The study yielded a description of parents' understandings of the nature and purposes of the groups and the interventions they attended. This description brought together in one place an overview of their experience and included a number of findings that supported discrete observations and suggestions extant in the literature. It also included findings that contributed to more nuanced evidence regarding ongoing parental confidence to use learned strategies following intervention, development of parental insight into their child's communication needs, and the impact of parent-based intervention on the parent-child relationship.

The subject of potential harm to parents in groups was another area where this study contributed several items of evidence. In terms of parental stress, findings in the current study supported previous evidence that providing intervention to their children can be a pressure on parents; however, on balance the parents in this study described being empowered rather than disempowered by their ability to help their child. They also identified groups as less stressful than individual sessions in terms of attention from professionals. Hence, one implication of this study could be that while intervention includes stressful elements, other aspects of the experience may act to counterbalance these.

Through drawing together the findings of the present study with models and observations based on data (Beresford, 1994; Gibson, 1995) and theory (Anderegg et al., 1992), an association between parent-based intervention groups and processes of parental adaptation, coping and empowerment has been postulated. However, the linking of group processes with adaptation, coping and empowerment in this study has taken place at a theoretical level;

the associations may be coincidental. Further studies to explore parents' perceptions of adaptation, coping and empowerment across a range of speech and language therapy interventions, and in the absence of intervention, would be helpful in determining whether this is the case. In addition, studies to investigate whether adaptation, coping or empowerment in parents of children with communication difficulties are associated with different outcomes for the parent, child, or family, could be indicated to inform decisions regarding whether to focus on these processes in clinical practice.

The study findings were also used to develop a tentative theoretical model of how parents may experience parent-based intervention groups. This model identified how different components of the group setting may interact to produce a unique environment, which contributes opportunities distinct from those offered by the components delivered separately.

The findings and theoretical model developed in this study reflected parents' experience of clinical intervention, and hence provide insights into how the intervention process worked from their perspectives. This has implications for clinical practice in the local context; findings will be disseminated to local clinicians to inform reflective practice and allow the views of parents to lead changes where necessary (Lyons et al., 2010). Some information may also be useful to other clinicians providing similar interventions, and by extension to other parents, so a further piece of work to disseminate these findings more widely could be required on ethical grounds (Oliver, 2003).

The descriptions provided by parents identified processes and practices that contributed positively or negatively to their experience and the outcomes

they perceived from the groups. Some of these were mechanisms such as the authority of other parents' views and effects of comparison, normalisation, and validation; awareness of the mechanisms identified could provide clinicians with opportunities to ameliorate or capitalise upon their effects during intervention. Parents also provided information about complete components of the courses, such as the significance of one-to-one appointments, the first group session, and the balance of supportive and educative experiences during group sessions, which could also inform clinicians' planning of particular sessions and of the intervention as a whole.

The process described by parents of weighing costs against benefits, and their views of what those costs were, provided information that could have implications for intervention planning and for service planning as a whole. Understanding the effort required to implement behavioural changes, and the emotional costs experienced by some parents, as well as confirming practical costs, may be helpful to inform the views of service providers about parental "non-compliance", and raise awareness of potential for harm to participants when benefits are reduced or costs increased.

Costs to parents are an unintended outcome of intervention, and for both ethical reasons and their impact on engagement (Glogowska & Campbell, 2000), clinicians and service planners may wish to reduce certain costs to parents when possible. However, a particular issue to be considered here would be the findings of this study that processes of empowerment and adaptation, although not formally stated as objectives of intervention, were a significant outcome for parents; some of the costs identified in the present study

may be inherent in the processes of personal change, adaptation and empowerment that occurred. A more explicit intentional focus on ensuring these outcomes for parents could be considered in order to maximise intervention benefits and obtain a more acceptable cost-benefit balance. Here again, information provided by parents in this study could be of use; they perceived several ways in which benefits from the group could be maximised, including ongoing support to maintain changes, enabling more fathers to attend sessions, and enabling other family members to access the intervention.

The study findings also have implications for policy and service design. The findings, and the theoretical model arising from them, indicated that parent-based intervention groups might not simply be a method of delivering parent-based input to several parents at once, nor of providing peer support alongside professional intervention, but that they are qualitatively different interventions that provide additional experiences unique to the setting with potentially different outcomes. If these experiences and outcomes are considered valuable by parents or clinicians, then the provision and funding of these groups cannot be viewed as interchangeable with provision and funding for “similar” individual interventions. Nor can the provision or otherwise of groups be decided based on cost-effectiveness comparisons between group and individual interventions if they are not in fact delivering all the same outcomes .

5.6 Limitations of the study

5.6.1 Limitations related to sampling and recruitment

Due to difficulty recruiting the number of volunteers originally envisaged, this study was completed using a convenience sample; this was similar to the experience of Fourie (2009) in his study of adults with acquired communication and swallowing disorders. The limits imposed by this restriction had implications for both the credibility and transferability (Lincoln & Guba, 1985) of the study findings. Despite extending the recruitment phase of the project by five months, the final sample in this study was smaller than originally planned, with ten participants rather than twelve. Nevertheless, it was a purposive sample, with participants meeting the study criteria, and the reduced sample size did not prevent data saturation for major codes and categories developed during data analysis. However, new details were continuing to arise during the final two interviews. This suggested that a larger sample could have provided richer data, and that the findings presented may not reflect the totality of parents' experiences.

Variation within the sample was limited in several ways. Apart from groups related to children who stammered, which were excluded by design, groups for several other diagnostic caseloads yielded no volunteers, so not all types of group were represented in the data generated. Representation of geographical caseloads was also limited; recruitment had taken place at groups held in rural areas, but all the study participants had attended courses run in the two main towns. While they did not all live in these towns, they all lived within half an hour's drive of the course they attended, which did not reflect a sector of

the sample population who live in more isolated areas and may drive for over an hour to attend appointments at their “local” clinic. The sample was also limited to native English speakers. This may have been because the courses were all delivered in English, but it is also possible that parents with English as an additional language might have attended the groups but preferred not to participate in interview research. In common with several other studies (for example Hayhow, 2009), the great majority of participants were mothers; as no attempt was made during recruitment to identify the proportion of fathers present, it is not possible to say whether this ratio reflects that of attendance at the groups. Difficulties in recruiting to the sampling frame also limited variation in terms of the length of time between group attendance and the research interview. If recruitment had been more successful, some volunteers would have been interviewed shortly after recruitment, and others invited after a delay of six months to a year. This would have introduced an element of maximum variation sampling for changes in perspective over time. However in the event, all volunteers were interviewed within four months of recruitment. The lack of variation in the sample with regard to these different factors may reduce the transferability of the study findings because they fail to reflect the experiences of a sufficiently broad range of parent-based intervention group attendees, and fail to explore changes in perception over time.

No particular reasons for difficulties in recruitment emerged during recruitment meetings, and it was not possible to pursue this with group providers due to the protocols in place to protect confidentiality. However, to address these limitations, future cross sectional studies could include a longer

recruitment phase to compensate for low recruitment rates. This would also facilitate the introduction of delays between recruitment and interview. Selective studies could target fathers, groups in rural areas, diagnostic groups not sufficiently represented in the current study, or parents for whom English was an additional language. The time-limited nature of the data was a feature of cross-sectional design; a longitudinal study would have allowed exploration of changes in perception over time. If commenced early enough, a longitudinal study could also have identified any progression of skills from a self-conscious to an automatic use on the part of parents.

A further limitation on transferability, and potential limitation on credibility of findings, resulted from the fact that this study recruited parents at the final session of parent-based intervention groups, in order to restrict the sample to parents who had completed the intervention. This could not guarantee that participants had attended the whole course; two participants in the current study had missed earlier sessions, and one of these participants provided interesting comments on the value of personal attendance relating to this. From this perspective, the choice to recruit from the final session did not threaten the quality of the data gathered, and the sample was consistent with the criterion of “completing the course”. However, as only those parents who had “stuck with” the course were interviewed, the study did not explore the perspectives of parents who declined, were unable to attend or complete, or opted out of courses. While there were good reasons for this in terms of the stated aim of the study there are implications for the transferability of findings, and may be implications for the objectivity of the data generated by the participants. The

sample was restricted to parents who may have been more comfortable with the interventions, found them more useful, were more motivated, or for whom the costs of attending were relatively less than perceived benefits. A longitudinal study commencing prior to a group would be helpful in addressing any potential bias, as this could include the views of parents who declined or did not complete the intervention.

The high proportion of children with diagnoses or potential diagnoses of autistic spectrum disorders represented in the sample may also have reflected a recruitment bias; possibly the parents of children with more pervasive communication difficulties, whether diagnosed or undiagnosed, valued an opportunity to talk about their experiences and were more likely to volunteer for interview. Unfortunately, no figures regarding the proportion of the local overall caseload with these difficulties have been gathered, so it is not possible to determine whether such a bias may exist in the sample. The implications of such a bias, should it exist, are considered below.

5.6.2 Limitations related to data generation and analysis

There were several limitations or potential limitations to this study related to data generation and analysis.

Three potential limitations related to participant “bias”. The data parents provided may have been positively biased towards parent-based intervention groups, as parents’ reported views of which interventions should be provided have been shown to correspond to the form of intervention received (Baxendale et al., 2001; Carroll, 2010). In addition, the majority of parents in this sample, who were living with a child with significant and pervasive communication

difficulties secondary to long-term conditions, may have placed more emphasis on experiences of adaptation or empowerment than parents in another sample would have done. Negative case sampling for parents of children with mild, short-term and primary communication difficulties would allow this second possibility to be explored.

The dual roles of researcher and clinician may also have influenced participant contributions. Parents may have attempted to give the researcher “correct” answers matching their perceptions of what professionals or other parents might think, rather than disclosing their own perceptions. They may have limited their responses, because they knew the researcher was also a local speech and language therapist. Conversely, they may have given selected information expecting it to be passed on. While this would have reduced the credibility of the study findings, there was no evidence that any of these had occurred in the current study, and the clinician/researcher role may have encouraged parents to disclose information that they would have withheld from a non-clinician.

Other limitations occurring in data generation and analysis were due to threats to the dependability of the research process and the detachment of the researcher. As Coffey and Atkinson pointed out, the final product in a study such as this is not a definitive description of “reality”, but one interpretation of a phenomenon produced by combining perceptions of the participants with perceptions of the researcher (Coffey & Atkinson, 1996). While this study explicitly sought to explore parents’ “subjective” perceptions of parent-based intervention groups, in developing a grounded description based on the data,

and particularly when developing interpretative theory and a theoretical model, the researcher is required to exercise more “objectivity” by maintaining an appropriate level of detachment.

The conflict between researcher and clinical roles initially limited the dependability of the interview process through a bias towards clinical interview techniques in earlier research interviews; the researcher took several data interview cycles to develop techniques appropriate to a “research” interviewer rather than a “clinical” interviewer.

There was also a risk that coding of the data, particularly in terms of identifying links and significance of codes, and theory building, would be influenced by the researcher’s dual role. While the researcher’s clinical insights may have been appropriately applied, no opportunity was built into the study design to revisit participants to clarify interpretations and thereby enhance credibility and confirmability.

5.7 Transferability of findings and theoretical generalisation

When considering the trustworthiness of a qualitative study, it is necessary to consider whether conclusions may transfer to other settings. This study sought to explore the experiences of a population served by a single speech and language therapy team. While other teams and populations may differ, a number of findings in the current study corroborated observations by other researchers, including observations relating to parent groups outside the field of speech and language therapy. Consequently, it is possible that the description presented in this study will reflect parents’ understandings of similar

groups elsewhere, and possibly in a number of disciplines. This cannot be assumed, but is ultimately a judgement for those with knowledge of the “other setting” to make (Lincoln & Guba, 1985).

Theoretical generalisation (Robson, 2011) may also be possible; the model presented in this study could be used as a tentative framework for exploring parent-based intervention group processes within various populations. Within speech and language therapy, the model may transfer to other carer populations, such as the partners of stroke patients. As some of the findings in the current study were similar to those relating to direct intervention groups (for example, Whitaker, 2001), the model may have descriptive and explanatory value for a range of groups where professionals and peer groups are present.

5.8 Conclusion

This study is situated in relatively new but developing contexts of grounded theory studies and qualitative explorations of parental perspectives in the field of speech and language therapy. It proceeded from ontological and epistemological positions of constructionism and interpretivism, as it was concerned with exploring the meanings parent-based intervention groups held for the parents who attended. The motivation to explore these meanings was based on awareness of evidence that parents and clinicians can perceive interventions differently (Glogowska & Campbell, 2000; Lyons et al., 2010), and the responsibility of clinicians to develop shared meanings with parents as a basis for more effective treatment (Lyons et al., 2010).

The aim of the study was to explore parents' and carers' experiences of attending parent-based intervention groups, thereby developing a preliminary understanding of these experiences. It was anticipated that such an understanding could inform clinicians' attempts to develop shared meanings with parents, identify helpful information regarding costs or potential harm to parents associated with the intervention, and contribute insights into how the intervention process worked.

The study was successful in meeting the objectives of exploring how parents understood the nature and purposes of parent-based intervention groups, identifying emergent objectives for the study (Charmaz, 2006), and developing a preliminary theoretical understanding of parents' experience of parent-based intervention groups. By exploring parents' perceptions using qualitative research strategy and grounded theory approaches, it was possible to obtain a wide-ranging and detailed description of parents' experiences, to make connections between these experiences and models of parental adaptation and empowerment extant in the wider literature, and to develop a theoretical model of how parents experience parent-based intervention groups.

The detailed description generated with the parents provided insight into the processes involved for them in attending parent-based intervention groups. It also provided insights into their understandings of the purposes of the groups, thereby laying a foundation for the development of shared meanings between speech and language therapists and parents, as advocated by Lyons et al. (2010) from the start of intervention. It provided information on the costs of intervention that parents perceived; when this was considered in connection

with the processes of empowerment and personal change that parents also described, the study provided evidence suggesting that the potential for harm to parents may be balanced by perceived benefits. The study also contributed insights into how parent-based intervention groups may work, through the descriptions provided by parents, connections made with models of parental adaptation and empowerment, and the theoretical model of parents' experience of the group setting which was developed.

This study contributes to the literature through an overview of parents' perceptions of parent-based intervention groups, an understanding of the possible role of groups in processes of parental adaptation and empowerment for parents of children with communication difficulties, and a theoretical model of how parents experience the groups that includes both descriptive and explanatory potential. This information has implications for clinical practice. It opens up this topic area for further research in several ways, and provides a tentative theoretical model that may be helpful in exploring parent-based intervention groups, and possibly other intervention groups, further.

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Appendix A

Description of literature search

Search terms

Potential keywords and their variants were first identified using a PICO framework (Population/Problem, Intervention, Comparison, Outcome) as a guide. The majority of keywords identified fell into the categories of Population/Problem, Intervention, and Outcome. These search terms were then applied to the academic and practitioner literature and refined. Search terms found to be effective were used to create email alerts so that subsequently published literature was also identified.

During literature searching, some new keywords were added as they were identified from the literature or from concepts arising from ongoing data analysis. Retrospective searches were carried out for these terms. However, some search terms identified in this way were found to be limited to particular contexts or periods.

All searches were limited to publications in English. Date limits were initially set at ten years, extending to fifteen years where there was a low hit rate. For concepts arising from the data, no time limit was set. This was to ensure as wide a view of previous literature as possible.

When searching catalogues and databases, keywords and search strategies such as truncation and use of Boolean operators were adjusted to the parameters of each organisation or search engine. For example, the search term “speech and language therapy” was necessary when searching an NHS library catalogue, but not when searching a specialist library catalogue.

The search terms used in the literature search are listed at the end of this Appendix.

Identifying and accessing sources

The sources used in this search were books (both academic and practitioner literature), journal articles, theses, and other “grey” literature such as documents from Government departments and other organisations. Items were accessed in hard copy or electronically.

The University of Chester holds only selected speech and language therapy references, so two additional libraries were used to identify and access further books and journal articles. Initial searches using the COPAC library catalogue showed that University College London was consistently cited as a repository for references identified by the search terms. This was due to the presence of the National Information Centre for Speech-Language Therapy (NICeST), and so the University College London library catalogue was subsequently used in preference to COPAC. The NHS hospital library serving Telford and Wrekin Primary Care Trust was also used.

Clinical and educational databases were searched because speech and language therapy is delivered in both settings. The databases searched were CINAHL, MEDLINE, AMED, Psychinfo, BEI, AEI and ERIC. Zetoc was also searched. Access to identified journal articles was through University of Chester and NHS Athens accounts, and through the three libraries identified above. The NHS Athens account was used to access Department of Health documents, the Cochrane database, and some journals. Index to Theses was used to identify relevant theses and those available electronically were accessed if appropriate through the British Library EThOS service.

Additional and primary references were identified through the reference lists and citations in key books and articles; no date limit was set on these. Citations of key journal articles were checked using the Web of Science citation index to identify references that were more recent; it was also possible to find citations of some key books using Google Scholar. Citation alerts were set up for a small number of key references, along with alerts from Zetoc for key search terms and journals to identify potential new information during the course of the study.

Search management and recording

A search log was kept using Microsoft Excel to record and organise search terms, and to track possible references as they were identified, located, accessed and read. Bibliographical information was recorded using EndNote X.

Search terms

speech language patholog*	speech and language patholog*	speech patholog*
speech language therap*	speech and language therap*	speech therap*
group treatment	group intervention	group therapy
parent group	parent based intervention	parent based
parent participation	mediated intervention	milieu teaching
Hanen		
parent* experience	parent* perspective*	parent percep*
carer* experience	carer percep*	
parent* adapt*	parent* adjust*	parent* resilience
parent* empower*	parent* coping	
child*	disab*	chronic

Appendix B

Letters confirming ethical approval



National Research Ethics Service

North Staffordshire Research Ethics Committee

North Staffordshire Medical Institute
Hartshill Road
Hartshill
Stoke-on-Trent
Staffs
ST4 7NY

Telephone: 01782 714980
Facsimile: 01782 714975

Dear Ms Moseley Harris

Study Title:

Parents' and carers' understandings of the nature and purposes of parent-based intervention groups delivered by the paediatric Speech and Language Therapy service in Telford & Wrekin and Shropshire Primary Care Trusts: an exploratory study.

REC reference number:

09/H1204/40

Protocol number:

1

Thank you for your letter of 12 May 2009, responding to the Committee's request for further information on the above research and for submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised and subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant letter 2 (transcription check)	1	30 September 2008
Initial Interview Guide	1	31 October 2008
Flowchart	1	02 March 2009
Statement of Indemnity Arrangements		01 August 2008
Letter of invitation to participant	1	30 September 2008
Letter from Sponsor		15 January 2009
Covering Letter		31 March 2009
Protocol	1	31 October 2008
Investigator CV		02 March 2009
Application		25 March 2009
Developing interview guide questions	1	31 October 2008
Reference List		02 March 2009
Student CV		02 March 2009
Participant Letter 3 (corrected transcript)	1	30 September 2008
Participant Information Sheet: Therapist	1	30 September 2008
Participant Letter 1 (Saturation)	1	12 May 2009
Response to Request for Further Information		12 May 2009
Participant Consent Form: Quotations	1	12 May 2009
Participant Consent Form	2	12 May 2009
Participant Information Sheet	2	12 May 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National

Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H1204/40

Please quote this number on all correspondence

Yours sincerely

for 

Miss Nicola Brooks
Chair

Email: barbara.cannings@uhns.nhs.uk

Enclosures: *List of names and professions of members who submitted written comments*
"After ethical review – guidance for researchers"

Copy to: *Professor Sarah Andrew, Dean of Applied and Health Sciences, University of Chester, Parkgate Road, Chester, CH1 4BJ*
Professor Miranda Thurston, Director, Centre for Public Health Research, University of Chester, Parkgate Road, Chester CH1 4BJ
R&D Department, Telford & Wrekin PCT and Shropshire PCT

North Staffordshire Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 01 June 2009

Miss Nicola Brooks	Solicitor	Lay member/Chair
Mr David Hunter	Lecturer in Ethics	Lay member
Mr Kelvin Jordan	Statistician	Expert member

NHS
Telford and Wrekin

Halesfield 6
Telford
Shropshire
TF7 4BF

Tel: 01952-580300
Direct Line: 01952-580480
Fax: 01952-582661

Confirmation of Approval of Research Study

Dear Barbara,

I can confirm that approval has been granted by the Telford & Wrekin PCT Research Management and Governance Office for the following research study, which falls under the requirements set out in the NHS Research Governance Framework.

Title: Parents' and carers' understandings of the nature and purposes of parent-based intervention groups delivered by the paediatric Speech and Language Therapy service in Telford & Wrekin and Shropshire Primary Care Trusts: an exploratory study.

Study Reference: SCTWPCT048

Chief Investigator: Prof Miranda Thurston

Sponsor: University of Chester

Funder: Self funded

Research Location(s): Various locations within Telford & Wrekin PCT

NHS Trust(s): Telford & Wrekin Primary Care Trust

Proposed local study end date: 30/06/2010

You may begin this research study within the Telford & Wrekin Primary Care Trust noted above.

Please read carefully, the following additional information that is applicable to this confirmation of approval.

Please note that your research study may be monitored or audited by this research office or other relevant authority as part of the requirements set out in the Research Governance Framework for Health & Social Care (2005).

In order for us to continue to meet the requirements for Research Governance you are requested to provide us with the following documents (electronic or paper) relating to this study:

- A copy of all COREC Annual progress report(s) (if applicable)
- A copy of the COREC End of study declaration
- A copy of the final report no more than 6 months after completion of the study
- A completed monitoring form for Department of Health reporting purposes (the form will be sent to you for completion)

You are also requested to notify us about any of the following that are applicable to the Trust(s) for which this approval applies:

- Amendments to any documents that require M/LREC approval
- Changes to study start and end dates
- Changes in personnel/members of the research team
- Any serious adverse events (e.g., SUSAR) within the timescales specified on the COREC website.

In addition, we will from time to time also request you to provide us with up-to-date details of all practices/ locations that you know will be, are or have been involved in this study.

Yours sincerely,



Helen Couth
Head of Clinical Governance (R & D Lead)

North Staffordshire **NHS**
Primary Care Trust

Shropshire County **NHS**
Primary Care Trust

South Staffordshire **NHS**
Primary Care Trust

Stoke on Trent **NHS**
Primary Care Trust

Telford and Wrekin **NHS**
Primary Care Trust

South Staffordshire RM&G Office
South Staffordshire Primary Care Trust
Anglesey House, Rugeley, WS15 1UZ
Tel: 01889 571814
Fax: 01889 571839
e-mail: Karen.Bond@southstaffspct.nhs.uk

Confirmation of Approval of Research Study

Dear Barbara,

I can confirm that approval has been granted by the Shropshire County PCT Research Management and Governance Office for the following research study, which falls under the requirements set out in the NHS Research Governance Framework.

Title: Parents' and carers' understandings of the nature and purposes of parent-based intervention groups delivered by the paediatric Speech and Language Therapy service in Telford & Wrekin and Shropshire Primary Care Trusts: an exploratory study.

Study Reference: SCTWPCT048

Chief Investigator: Prof Miranda Thurston

Sponsor: University of Chester

Funder: Self funded

Research Location(s): Various clinics within Shropshire County PCT

NHS Trust(s): Shropshire County Primary Care Trust

Proposed local study end date: 30/06/2010

You may begin this research study within the Shropshire County Primary Care Trust noted above.

Please read carefully, the following additional information that is applicable to this confirmation of approval.

Please note that your research study may be monitored or audited by this research office or other relevant authority as part of the requirements set out in the Research Governance Framework for Health & Social Care (2005).

In order for us to continue to meet the requirements for Research Governance you are requested to provide us with the following documents (electronic or paper) relating to this study:

- A copy of all COREC Annual progress report(s) (if applicable)
- A copy of the COREC End of study declaration
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- A completed monitoring form for Department of Health reporting purposes (the form will be sent to you for completion)

You are also requested to notify us about any of the following that are applicable to the Trust(s) for which this approval applies:

- Amendments to any documents that require M/LREC approval
- Changes to study start and end dates
- Changes in personnel/members of the research team
- Any serious adverse events (e.g., SUSAR) within the timescales specified on the COREC website.

In addition, we will from time to time also request you to provide us with up-to-date details of all practices/ locations that you know will be, are or have been involved in this study.

Yours sincerely,



Bharti Patel-Smith
Clinical Governance Manager (R & D Lead)
Shropshire County PCT

Appendix C

Therapist Information Sheet

Information about the research project
“Exploring parents' experiences of speech and language therapy groups”

What is the research about and why is it being done?

Speech and language therapists have been running parent based intervention groups for some years, but the evidence base regarding parents' and carers' experiences of these interventions is minimal. This is an exploratory study; the aim is to discover more about parents' perspectives of such groups. It is not an audit, though I hope to identify general aspects of parents' experiences which are helpful in understanding the treatment we provide in a group setting.

I am undertaking this research study as part of an MSc in Research Methods at the University of Chester.

What general methods will be used?

This is a qualitative study. Data will be generated through semi-structured interviews and a grounded theory approach to data analysis will be used.

Who will be eligible to take part in the study?

The sample population will consist of parents and carers who have attended one or more parent based intervention groups provided by the paediatric speech and language therapy service within both Shropshire and Telford and Wrekin PCTs. The range of speech and language therapy difficulties covered will be determined during the study, but will not include dysfluency since my close association with that caseload may influence the data generated.

A pool of volunteers will be recruited from the sample population and purposive sampling will be carried out. There will be two stages to this; initial maximum variation sampling, followed by theoretical sampling of later participants as the initial data analysis indicates particular avenues for further investigation. The sample will be small – just twelve participants.

Will the study influence treatment or caseload management for my clients?

This study should not influence any intervention decisions. You will know which parents on your caseload have been invited to take part in the study, but the names of volunteers and final participants will be kept confidential. Each child's speech and language therapy should carry on just as it would have done anyway. I will not treat or offer advice about any of the children of participants, nor will I need to look at their case notes.

Why won't we be told who has volunteered?

There are several methodological and ethical reasons for this. As data is being generated from a small sample with specialised needs, anonymity will be extremely difficult to maintain if the participants' identities are known. There is also a risk that knowing participants' identities might influence therapists' practice. Participant confidentiality reduces both these risks. Thirdly, parents may be more forthcoming about their experiences and feelings if they know their participation will be kept confidential. Finally, there is some evidence in the literature (Glogowska, Roulstone, Enderby, Peters, & Campbell, 2001) that research participants may perceive

participation as yielding treatment advantages. It is hoped that telling parents that their SLT does not know of their participation will reduce or eliminate this erroneous perception of an advantage which does not in fact exist.

Will I be expected to do anything?

If you run parent based intervention groups you may be asked to help with recruitment of volunteers. This would involve arranging an additional twenty minutes on the final session of one or more courses which you run, to allow me to introduce myself and the research study to your group members. You would not be expected to sit through this; in fact it is important that you are not present to preserve confidentiality and prevent inadvertent influence.

Can I do anything to encourage parents to participate, or help you select particularly articulate participants?

It is important for methodological and ethical reasons that you do not express any opinion to parents in your groups on whether they should or should not participate in this research. Please remain neutral and refer parents back to me if they have any questions.

Although I hope to encounter participants who can give me useful information, sampling methodology problems will arise if you select or screen out anyone from the sample population.

Shouldn't involvement in research be documented in the case notes?

Yes, the consent form should be placed in the notes, so in order to fulfil this requirement and allow for confidentiality during the study, my research protocol states that the record will be completed at discharge or after five years, whichever is the sooner.

What information are you giving to the parents and carers?

All parents who are approached will receive an information sheet. A copy is attached for your information.

What should I do if parents tell me they have been interviewed, or want to discuss the research with me?

Because of the issues mentioned above, it is important that your reaction is neutral. If the parent has queries or problems about the research, please direct them to the appropriate contact addresses on the participant information sheet.

What about disseminating the research?

As well as writing my dissertation, I shall be providing anonymised feedback to the SLT team as a whole once the data has been analysed.

Glogowska, M., Roulstone, S., Enderby, P., Peters, T.J., & Campbell, R. (2001). Who's afraid of the Randomised Controlled Trial? Parents' views of an SLT Research Study.

International Journal of Language and Communication Disorders, 36 (supplement), 499-504.

Appendix D

Documents relating to informed consent

D.1 Participant Information Sheet



Information about the research project

"Exploring parents' experiences of speech and language therapy groups"

Please read this sheet carefully, and take some time to decide whether you would like to take part in this research. Talk to other people first if you want to.

Who is doing the research?

My name is Barbara Moseley Harris. I am a Speech and Language Therapist working in Shropshire and studying for a degree in Research Methods at the University of Chester. This research is part of my course.

What is the research about and why is it being done?

Speech and language therapists have been running parents' groups for some years, but we know very little about what it is like to be a parent or carer at these sessions. I am inviting you to take part in this research project because you have been to one or more of these groups and I am interested in hearing about your experiences. Your views could help me to gain a clearer picture of how it feels to be in the speech and language therapy groups offered in Shropshire. I hope that this information can then be used to improve our work locally, and perhaps help speech and language therapists in other parts of the country too.

Will the research affect my child's treatment?

No. This research is completely separate from your child's treatment. Their speech and language therapy will carry on just as it would have done anyway. Your speech and language therapist knows I am telling you about this project, but she will not be told whether you decide to take part and I will not treat your child or see their case notes.

What will I need to do if I decide to take part?

If you decide to take part you will need to send me your contact details on the attached form. At a later date I will ring you and check whether you are still happy to be involved. If you are, I will arrange to meet you either at a clinic or at your home, depending which you would prefer.

When we meet, I will give you a consent form to sign, and I will ask you about what it was like being in the parent group(s). I will record our conversation. I may also jot down some notes as we talk, to help me be sure that I've covered everything. This is the research interview and it will take about one hour. If you choose to be interviewed at home, I will be with you for about an hour and a half because I will need time to set up the recorder and pack away afterwards.

After the interview, I will give you a second form to fill in and sign. This will tell me whether I have your permission to use direct quotations of the words you have used in the interview. I will take the recording away and type up what we both said. I will leave out any names you have used, to protect your privacy. I will then send you a copy of the typed interview, in case you want to correct anything or make anything clearer. After this you will not need to do anything else, unless you have decided that you want to see any quotations I would like to use. If you do want to do this, I will write to you with details of any quotations at a later date, and you will need to let me know if you agree to your words being used.

I will interview one person at a time, so I may not contact you for some time. All the interviews will happen within the next twelve months. I may not need to interview everyone who volunteers. If I do not need to interview you I will write to you to let you know.

What happens to the information I give?

I will look at the typed interviews and try to work out what the main issues are from what you and other parents have said. I will write some reports about this, one for the University and another for Shropshire speech and language therapists (I will include suggestions about improving our work). If it might help to improve the work of speech and language therapists in other parts of the country, I will also write a report for national publication. In all these reports I might use direct quotations of your own words if these help to make a point clear, but I will not name you or use any details which could trace the quotations back to you. I will only use direct quotations if I have your consent to do so.

Everything you tell me will be stored following the rules set out in the Data Protection Act*, including keeping your details secure. I will not normally allow anyone else to see your information apart from my supervisor at the University. However, I am not allowed to keep private anything you tell me which could protect you or someone else from harm. Occasionally researchers have their studies checked or audited to make sure that they are conducting the research in a proper and professional manner; this might also involve the auditors seeing your information. You would be informed if this was going to happen.

I will keep the information you give me for ten years after my reports are handed in. I will not use it for any other research in that time. Other people will not be allowed to use it and after ten years it will be destroyed.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time. You do not have to give a reason for this. There is no penalty for deciding not to carry on, and your child's care will not be affected in any way. If you decide not to go ahead with the study you can choose whether anything you have already told me can be used in the research or not.

Are there any advantages or disadvantages to taking part?

The project is not designed to have any particular advantages or disadvantages for you or your child. Of course I will be taking up some of your time if you choose to take part, but I hope you will find it interesting to be involved in this research.

Is there anything else I should know?

If you decide to take part in the project, a copy of the consent forms that you sign must go into your child's speech and language therapy case notes. However so that you can be sure that this information is kept confidential while your child is receiving treatment, this will not happen until your child's treatment is finished or five years have passed.

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This is to protect your safety, rights, wellbeing and dignity. This study has been reviewed by North Staffordshire Local Research Ethics Committee. My manager also knows about this project.

As part of the Research Ethics Committee process, I have to decide whether, if something happens to you that means you are no longer able to give consent for the research, I would use the information you have already given me. I have decided that I would use it, because I will only collect and use the information if you have already given me permission to do so.

What if there is a problem at any stage?

If you feel concerned about the research at any stage, and I cannot help you, you can contact Pamela Devall, Research Governance Lead, at:

South Staffordshire Primary Care Trust, Anglesey House,
Rugeley, Staffordshire, WS15 1UZ

Telephone: 01889 571817

Where can I find out more?

If anything written here is not clear, or you have any questions about the research, please contact me:

**Barbara Moseley Harris, Children's Therapy Services,
Coral House, Longbow Close, Harlescott Lane, Shrewsbury, SY1 3GZ**

Telephone: 01743 450800

If you have any questions about research generally, or want independent advice about taking part in research, you can contact INVOLVE at:

INVOLVE
Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD

Telephone: 02380 651088

INVOLVE can also provide a Public Information Pack (PIP) about research, which is available from the above address or through their website at www.invo.org.uk

Thank you for taking the time to read this.

*see [http://www.ico.gov.uk/what we cover/data protection/the basics.aspx](http://www.ico.gov.uk/what_we_cover/data_protection/the_basics.aspx)

D.2 Interest form



INTEREST FORM

Title of Project: **Exploring parents' experiences of speech and language therapy groups**

Name of Researcher: **Barbara Moseley Harris**

Date of group meeting: _____

If you would like to take part in this research study please fill in two copies of this form. You should keep one copy for yourself and return one copy to me in the stamped envelope provided.

1. I am interested in taking part in the above study and I can be contacted at the address and phone number below.

☐

2. I understand that I may not be asked for an interview and that I will be informed if my help is not needed.

☐

Name _____

Address _____

Telephone number _____

Signed _____ Date _____

Copies when completed: 1 for participant; 1 for researcher file

D.3 Consent form



CONSENT FORM

Title of Project: **Exploring parents' experiences of speech and language therapy groups**

Name of Researcher: **Barbara Moseley Harris**

1. I have read and I understand the information sheet 'Information about the research project "Exploring parents' experiences of speech and language therapy groups"'. I have had the chance to think about the information, to ask questions and I have had answers that satisfy me. ☐
2. I understand that I do not have to take part in this research and that I am free to withdraw at any time without giving any reason, and my child's care will not be affected by this. ☐
3. I agree to the research interview being recorded. ☐
4. I understand that information collected during the study may be looked at by the researcher's supervisor. ☐
5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Chester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
6. I understand that if I later lose the capacity to consent to taking part in this research, the researcher will use the information she has already collected with my previous consent. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature

Name of researcher	Date	Signature

Copies when completed: 1 for parent; 1 for researcher file; 1 (original) for case notes at discharge.

D.4 Quotation consent form



QUOTATION CONSENT FORM

Title of Project: **Exploring parents' experiences of speech and language therapy groups**
Name of Researcher: **Barbara Moseley Harris**

In my reports about this research, I might want to use direct quotations of your own words if these help to make a point clear. If I do this, I will not name you or use any details that could trace the quotations back to you.

Please read the following options and tick the one you agree with:

8. I agree to any direct quotations being used. ☐
9. I want to see any direct quotations before agreeing to them being used ☐
10. I do not want any direct quotations to be used ☐

_____	_____	
_____	_____	
Name of Participant	Date	Signature
_____	_____	
_____	_____	
Name of researcher	Date	Signature

Copies when completed: 1 for parent; 1 for researcher file; 1 (original) for case notes at discharge.

D.5 Transcript check letter

Tel: 

date

Dear ...,

Thank you for taking the time to be interviewed on ...

I enclose a copy of the interview as I have typed it up. I have included everything that was said, such as “ums” and “ers”, and any sentences we didn’t finish. This is normal practice for this type of research. I have changed any names we used to letters of the alphabet, so that anyone reading this would not be able to tell who you are or where you are from. This is so I can protect your privacy. The letters I have used are: (list any used, e.g. C for your child, P for you, T for the speech and language therapist)

Please could you look through this and let me know if there is anything you wish to correct or make clearer. You can do this by phoning me on 01952 567800, or by writing any comments on the copy and sending it back to me in the stamped envelope provided. I will then send you a corrected copy.

If there are no corrections or other points then you do not have to do anything. If I do not hear from you by ... then I will take this copy as a correct record and use it for my research.

Thank you once again for your time and ideas. The information you have given me will be a great help for this research study. Wishing you and your child all the best,

Yours sincerely,

Barbara Moseley Harris

Appendix E

Initial interview guide

Interview guide

Thank you for agreeing to do this interview. I'm going to begin with some background questions and check that the tape recorder is working properly.

Today is... (date) and this conversation is about your experience of speech and language therapy groups run for parents and carers.

Have you just been involved in one group, or have there been others?

[If more than one] How many different groups have you been to?

[For each group] And how old was your child when you were involved in... (specify group)?

Now we'll just check that the recorder is picking up OK

OK. Now I'm going to ask you some more questions. There are no right or wrong answers, because I just want to find out what your views are.

Now, could you please tell me about the group(s) you've been to?
[Probes: What were they like? What happened?]

How did you decide whether to go to the group sessions?

Can you tell me how your child's talking was in the past?

How is their talking now?

What did you think about being asked to come to sessions (by) yourself?

Thinking about the fact that these were group sessions – how do you think that made a difference?

Do you think the group has had any effects? [Probe: what effects has it had?]

You've told me about how you see things now (saw things then). Did (Do) you see things differently before (now)? [How?]

And for my last question, how would you help another parent to decide if they should come to the group(s) you went to?

Those are all my questions. Do you have any questions for me before we finish?

The next thing that will happen is that I'll send you a copy of this interview as soon as it's typed, in case you want to add any comments.

Appendix F

Project management chart

Time →	
Literature review	
Literature searches	
Analysis of literature	
Project organisation	
Negotiate with NHS trusts	
Write research proposal	
Source recording equipment	
Ethical issues	
Develop/amend participant paperwork	
Prepare & submit ethics proposal	
Ethics committee amendments	
Data gathering and analysis	
Develop/amend interview guide	
Recruitment meetings	
Interviews, transcription & transcript check	
Initial coding	
Focused coding	
Comparative coding	
Narrative coding	